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Readiness for Living Independently among Emerging Adults with Type 1 Diabetes

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Abstract

Purpose—The purpose of the study was to examine the association of time (high school to post), living situation (independent of parents or not), diabetes-specific self-efficacy, and worry about hypoglycemia and how diabetes-specific self-efficacy and worry about hypoglycemia are associated with diabetes management among emerging adults with type 1 diabetes.

Methods—Participants (N = 114) completed measures on diabetes management, diabetesspecific self-efficacy, and worry about hypoglycemia during the last 6 months in high school (T1) and diabetes management, diabetes-specific self-efficacy and living situation post high school (T2). General linear mixed model for the diabetes management outcome was used to test associations with diabetes-specific self-efficacy, worry about hypoglycemia, time, and living situation independent variables. Moderation by diabetes-specific self-efficacy and worry about hypoglycemia was also tested.

Results—Diabetes management increased from high school to post, but was not significantly associated with living situation (independent of parents or not). Diabetes management was better for youth with greater diabetes-specific self-efficacy. However, neither diabetes-specific self-efficacy nor worry about hypoglycemia moderated the relationship between diabetes management and time or between diabetes management and living situation.

Conclusions—Diabetes management improved over time for these emerging adults with type 1 diabetes. Diabetes-specific self-efficacy is important for diabetes management no matter if youth are in high school or post-high school and if living with parents or not.

A critical developmental time for youth with type 1 diabetes is emerging adulthood. ^{1, 2} This newly recognized developmental period, from about 18 to 25 years plus years of age, is known as a time during which youth experience increasing freedoms and many changes.³

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The early years may be especially challenging; these youth are graduating from high school, a major rite of passage,⁴ and undergoing a major move, leaving the parental home.⁵ Up to 56% of emerging adults in general ^{6,7} and 52% of those with type 1 diabetes ⁸ live independently of parents. The worsening of glycemic control during the early years of emerging adulthood around 17–19 years of age ^{9,10} may be an indication of the challenges these youth may be experiencing. Glycemic control is influenced by diabetes management, ¹¹ which may be particularly challenged as these youth adjust their routines for checking glucose levels, administering insulin, managing hypoglycemia, having regular meals, and exercising. It is likely that diabetes management worsens during this developmental transition and for those who transition to independent living; however, no known published study has examined the changes in diabetes management in relation to these transitions.

Emerging adults' readiness for these transitions could be associated with individual characteristics such as diabetes-specific self-efficacy ^{12–16} and worry about hypoglycemia, ¹⁷ known to be associated with diabetes management for younger age groups. These youth need to rely more on themselves because of the great freedoms experienced during this developmental period ³ and less proximity to parental support for their diabetes tasks, especially if they have moved out of parental homes. Youth with greater diabetes-specific self-efficacy may be more likely to move to independent living and maintain good diabetes management. In contrast, those with low diabetes-specific self-efficacy and poor diabetes management may be more likely to remain at home. Emerging adults with high levels of worry about hypoglycemia would be concerned that parents would no longer be immediately available for assistance with hypoglycemic events if they moved out of parental homes. However, that lack of assistance may not be a concern for those with low levels of worry about hypoglycemia. No known published study has examined the influence of diabetes-specific self-efficacy and worry about hypoglycemia on diabetes management during these transitions.

This study addresses the little researched population of emerging adults with type 1 diabetes, and could expand the understanding of these youths' readiness for major transitions. Thus, the purpose of this study was to examine the association of time (high school to post) and living situation (independently of parents or not) with diabetes-specific self-efficacy, worry about hypoglycemia, and diabetes management, and how diabetes-specific self-efficacy and worry about hypoglycemia are associated with diabetes management among emerging adults with type 1 diabetes. For emerging adults with type 1 diabetes, it was hypothesized that:

- a. diabetes management will worsen over time (high school to post);
- **b.** diabetes management will be worse for those living independently of parents than for those who do not; and
- **c.** diabetes-specific self-efficacy and worry about hypoglycemia will moderate the relationships between time (high school to post) and living situation (independently of parents or not) with diabetes management.

Methods

Design

This report utilizes data collected from an ongoing longitudinal study of the transition to young adulthood among youth with type 1 diabetes. Such a design had advantages over cross-sectional designs, providing a description of change of salient constructs and behaviors during developmental periods. ¹⁸

Procedures

The targeted sample was high school seniors with type 1 diabetes and they were recruited from outpatient diabetes care clinics of a regional university medical center, a private hospital and a regional diabetes care center. Participants were enrolled either face-to face at a clinic appointment or via the telephone after patients and their parents received a brief study summary from their health care provider. Inclusion criteria were: being 17 – 19 years of age and in the last 6 months of high school; diagnosed with type 1 diabetes for at least one year; able to speak and read English; and living with their parent or guardian. Potential participants were excluded if they had a serious psychiatric disorder or a second chronic illness that would interfere with becoming independent. The study received approval from the appropriate Institutional Review Boards. Consents were obtained from participants 18 years of age and older while for those who were under 18 years of age, assents were obtained from participants and consents from parents.

Participants completed questionnaires using Web-based entry, with some choosing a paper option. Time 1 (T1) data were collected at baseline during the last six months of high school and time 2 (T2) data were collected in the fall of the year post high school graduation (September through mid-December). The time interval between T1 and T2 ranged from 91 to 311 days with a mean of 192.39 (SD = 48.90). Data were collected on diabetes management and diabetes-specific self-efficacy at both T1 and T2, on worry about hypoglycemia at T1 only, and on living situation at T2.

Measures

Socio-demographic and Diabetes – related Data—were assessed at T1 and T2. At T1, participants were asked questions regarding their age, parental education and marital status. Participants' responses to T2 questions about their living situation (parents, roommates, etc.) were categorized as either living independently of parents or not. HbA1c (done using a standardized assay, either on the DCA2000, A1c Now kit or BioRad D10) was obtained from medical records as a measure of glycemic control at T1.

Diabetes Management—was measured by the 24-item Emerging Adult Diabetes Management Self-Report that measures management of diabetes related to diet, exercise, blood glucose testing, insulin administration, and hypoglycemia for either conventional or flexible regimens. This measure is an adaptation of the reliable and valid Diabetes Self-Management Profile (DSMP) ¹⁹ from an interview format for use with adolescents to a selfreport for cognitively mature emerging adults. Although adaptations of the DSMP to selfreport have recently been published, ^{20, 21} this study conducted its own adaptation since the study was initiated prior to those publications. In contrast to Wysocki's ²⁰ recently published self-report where participants were asked questions in relation to past month, participants in this study were asked to respond in relation to the past 3 months to be consistent with other measures collected every 3 months in the larger study. In a forced-choice format, participants were asked to respond to how often they performed diabetes tasks as well as what changes they made to their regimen given specific situations. Summed score for total management provided potential ranges of 0-84 and had a Cronbach alpha value of 0.77. Per the recommendation of the DSMP developers, ¹⁹ only the total management scale was used, since the subscales for diet, exercise, blood glucose testing, insulin administration, and hypoglycemia management did not have adequate reliability in that study (alpha coefficients less than .50) nor in the present study of older youth (alpha coefficients less than 0.65).

Diabetes-specific Self-Efficacy—was measured by a revised 8-item Diabetes Self-efficacy Scale ²² that measured youth's beliefs regarding their confidence in their diabetes care abilities. The original 7-item scale was revised to 8 items, differentiating treatment of

hypoglycemia and hyperglycemia as well as reflecting contemporary diabetes treatment. The 8 questions were related to taking insulin correctly, eating right for your diabetes, testing blood glucose at least 3 times a day, fitting exercise into your treatment plan, treating low blood sugar, taking steps to prevent low blood sugar, remembering to do everything and making adjustments for high blood sugars. Using a rating format, participants graded themselves on how well they could do tasks, ranging from an "A+" designating "*could not do better*" with a score of 9 to an "F" designating "*you are a disaster*" with a score of 1. Summed scores could range from 8–72. Cronbach's alphas were .78 for the 7-item scale ²² and .85 for the adapted 8-item scale in this sample.

Worry about Hypoglycemia—was measured by the Worry Subscale of the Hypoglycemia Fear Survey. ²³ The original subscale had 17 items, and was revised to 18 items for this study. The item appearing drunk or stupid was separated into two items because this age group would conceive of being drunk and being stupid differently. Participants were asked to rate how often they had worried with potential responses from 1 (*never*) to 5 (*very often*). Responses were summed for an overall score, with a potential range of 18–90. Cronbach's alphas for the worry subscale were .88 with a sample of adolescents, ²⁴ .89 with a sample of adolescents and adults ²³ and .93 in this sample.

Data Analysis

First, descriptive statistics were computed to describe the sample in terms of diabetes-related (such as HbA1c and duration of diabetes diagnosis) and socio-demographic (such as age, race, and gender) variables as well as the variables of interest (self-efficacy, worry about hypoglycemia, and diabetes management). Next, diabetes management outcome was modeled over time using a general linear mixed effects model (GLMM). This modeling strategy is also known by various other names, such as hierarchical linear modeling or random effects modeling. While similar in purpose to traditional repeated measures analysis of covariance, a GLMM approach has several advantages. In GLMM, missing data at one or more time points does not result in loss of the subject or available data. In addition, the GLMM strategy allows for time-varying covariates, flexible covariance structures, and subject-specific effects.²⁵ An unstructured covariance structure was used to model the variance and covariance among the two repeated measures within each subject. Time was treated as a fixed effect. Covariates included living independently at T2, diabetes-specific self-efficacy (time-varying, since measured at both T1 and T2) and worry about hypoglycemia (measured at T1 only). Moderation effects were tested by including interaction terms between time, living independently and the other covariates. For the diabetes management outcome, a full model with main and interaction effects was specified first (intercept; time; living independently; diabetes-specific self-efficacy; worry about hypoglycemia; time with living independently, diabetes-specific self-efficacy and worry about hypoglycemia; and living independently with diabetes-specific self-efficacy and worry about hypoglycemia). Non-significant interaction effects were subsequently eliminated from the model. All models were estimated using the PROC MIXED procedure available in SAS/ STAT software using a .05 level of significance.

Results

Participants

For this report, the sample consisted of high school students recruited in the first three years of the study. Table 1 provides a description of the sample. The sample was composed of 114 youth (M age = 18.3, SD = 0.4; range = 17.3-19.6) with type 1 diabetes who graduated from high school in May/June of the year and who had complete data for the selected variables at T1 and T2. Most participants were White (94.7%) and female (58.8%). At T1, 49.1% of

participants were on insulin pumps; they had had a diabetes diagnosis for an average of 8.6 years (SD= 3.9; range = 1.1 - 17.2) and the 110 with HbA1c data had an average value of 8.5% (SD = 1.4; range = 6.2 - 14.0). At T1, a considerable portion lived with both of their parents (60.5%) and high school was the highest level of education for most of the parents (47.7% for mothers and 43.4% for fathers). Although all lived with at least one parent at T1, most lived independently of their parents (56.1%) and were enrolled in college (80.7%) at T2. If they were living independently of parents at T2, they lived an average of 125.70 (SD = 158.25; range = 0 - 1000) miles from them. At T2, 24 (21.1%) reported hypoglycemic events requiring help and only 1 reported a hypoglycemic event with a seizure. For these first three years of recruitment, the participation rate was 85% and the attrition rate was 19% for this follow-up period.

In terms of variables of interest, average worry about hypoglycemia score was 35.8 (SD = 12.2, range = 18–76) at T1. Average diabetes-specific self-efficacy score was 53.4 (SD = 11.0, range = 9–71) at T1 and 54.2 (SD = 10.4, range = 24–72) at T2. At T1, the average for diabetes management score was 50.5 and 52.8 at T2.

Testing of Hypotheses

The first hypothesis was that diabetes management will worsen over time (high school to post). In the model containing all variables of interest (time, living independently, diabetes-specific self-efficacy and worry about hypoglycemia, participants demonstrated an increase in diabetes management (Beta=1.76, p=.006) from T1 to T2 over and above other variables in the model. However, this was in the opposite direction of the hypothesis that diabetes management would worsen.

The second hypothesis was that diabetes management will be worse for those living independently of parents than for those who do not. In the model containing all variables of interest (time, living independently, diabetes-specific self-efficacy and worry about hypoglycemia, participants did not demonstrate a significant increase in diabetes management based upon whether they lived independently or not from parents post-high school (Beta=-2.59, p=.070). This hypothesis was not supported.

Although not a separate hypothesis, there was a significant finding for diabetes-specific selfefficacy, but not for worry about hypoglycemia. In the model containing all variables of interest (time, living independently, diabetes-specific self-efficacy and worry about hypoglycemia, participants with greater levels of diabetes self-efficacy demonstrated a significantly higher level of diabetes management (Beta=.68, p<.001). However, worry about hypoglycemia was not a statistically significant independent predictor of diabetes management.

The final hypothesis was that diabetes-specific self-efficacy and worry about hypoglycemia will moderate the relationships between time (high school to post) and living situation (independently of parents or not) with diabetes management. Interactions between time and diabetes-specific self-efficacy and worry about hypoglycemia as well as interactions between living situation and diabetes-specific self-efficacy and worry about hypoglycemia were examined; however, no interactions were statistically significant. This hypothesis was not supported.

Discussion

This sample of emerging adults with type 1 diabetes did experience some changes in their diabetes management during this transitional period. Diabetes management increased from high school to post high school time period. These findings are contrary to the hypothesis

Diabetes management is associated with diabetes-specific self-efficacy but not with worry about hypoglycemia for these emerging adults with diabetes. Better management is associated with better self-efficacy and is consistent with existing evidence.^{12, 13, 15, 16,} Although diabetes-specific self-efficacy is important for diabetes management, self-efficacy did not moderate the relationship of management with living situation nor time from high school to post high school for these youth. This suggests that the association of diabetes-specific self-efficacy with diabetes management did not vary over time (high school to post-high school) or with living situation (living independently or not of parental homes) for youth in this study. In addition, worry about hypoglycemia did not interact differently with diabetes management over time (high school) or with living situation (living independently or not of parental homes) for youth in this study.

Limitations of the study need to be considered. Generalizability of findings from this study is limited to similar samples of youth with type 1 diabetes. These youth's average glycemic control of 8.5% indicates poorer control than ADA's and ISPAD's goal of HbA1c less than 7.5%. ^{26, 27} However, this sample had similar glycemic control levels as a sample of late adolescents who were intensively managed,¹⁰ but better glycemic control than a more representative sample of late adolescents.⁹ Youth in this sample also did not have high levels of diabetes management and this is consistent with poor diabetes management know to occur during adolescence.²⁷ The portion of youth with diabetes living independently of parents in this study was similar to the portion of type 1 diabetes ⁸ and the general population who lived independently.^{6, 7} However, this sample may be unique because those with co-morbid conditions impacting independence and management were excluded and a considerable portion of parents were married and had a relatively high level of parental education. Other important transitional events such as transfer from pediatric to adult care providers were not examined in this study with a limited sample size. Finally, this sample was recruited from three different sites and the possibility of differences among the settings exist; however, that diversity adds to the generalizability of the findings.

High school students who are about to graduate from high school and/or move out of parental homes need to be assessed for their readiness for these transitions. The findings from this study provide some evidence to guide transition planning for health care providers working with emerging adults. Diabetes management did not decrease over time; however, there is room for improvement in management. The average high school and post high school scores (50.5 and 52.8) on diabetes management, although greater than the scale's midpoint of 42, is not close to the highest potential score of 84. In addition, diabetes-specific self-efficacy needs to be assessed and considered in developing transition plans for these emerging adults. Although diabetes-specific self-efficacy did not moderate the relationship between diabetes management and time and between diabetes management and living situation, youth with better self-efficacy had better management. Youth with low diabetes-specific self-efficacy may need extra time where parents and youth share diabetes care; existing evidence indicates that parents and younger adolescents who share diabetes care have greater diabetes-specific self-efficacy.²⁸

Further research examining the effect of transitional events on specific aspects of diabetes management with a larger sample is needed, along with exploration of other influential factors and over a greater period of time. For example, quality and amount of parental support could provide more information than living independently of parents, a proxy for

immediate availability of parental support. Further, the exploration of other transitional events such as moving from pediatric to adult care providers is advocated in this age group. Examination of specific aspects of diabetes management and how youth provide structure or adapt routines around them may also be especially important to study. Development and testing of interventions targeted at enhancing diabetes-specific self-efficacy are also suggested by this study's findings. Interventions demonstrated to be effective could then be incorporated into transition programs for these youth.

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Table 1

Sample Characteristics (n=114 unless otherwise noted).

| Characteristics at T1 | Categories | Percen |
|---|----------------------------------|--------|
| Race | Black | 4.4 |
| | White | 94.7 |
| | Other | 0.9 |
| Insulin Administration | Injection | 50.9 |
| | Pump | 49.1 |
| Diabetes Regimen | Conventional | 7.9 |
| | Flexible | 92.1 |
| Living Situation | Only mother or only father | 14.9 |
| | Both mother/father in same house | 60.5 |
| | Father and step-mother | 1.8 |
| | Mother and step-father | 14.0 |
| | Part time with each parent | 5.3 |
| | Other adult/guardian | 3.5 |
| Parents' Marital Status | Married | 61.4 |
| | Divorced | 29.8 |
| | Other | 8.8 |
| Mother's Education | Less than High School | 1.8 |
| | High School Degree | 47.4 |
| | Associate or Vocational Degree | 14.9 |
| | Four Year College Degree | 22.8 |
| | Master's Degree or Higher | 13.2 |
| Father's Education (n = 113) | Less than High School | 6.2 |
| | High School Degree | 43.4 |
| | Associate or Vocational Degree | 7.1 |
| | Four Year College Degree | 25.7 |
| | Master's Degree or Higher | 16.8 |
| | Refused | 0.9 |
| Insurance Status (n = 110) | Private/commercial | 66.4 |
| | Public | 16.4 |
| | Other | 17.3 |
| Characteristics at T2 | | |
| For those living independently of parents, living with (n=55) | Friends | 5.5 |
| | Boyfriend/Girlfriend | 7.3 |
| | College Roommate | 83.6 |

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| Characteristics at T1 | Categories | Percent |
|--|------------------------|---------|
| | Alone | 3.6 |
| For those living independently of parents, place where living (n=53) | House owned by parents | 0 |
| | Rented house/condo | 3.8 |
| | Rented apartment | 9.4 |
| | Dorm | 75.5 |
| | Sorority/Fraternity | 1.9 |
| | Other | 9.4 |