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Initial Findings: Primary Diabetes Care Responsibility among Emerging Adults with Type 1 Diabetes Post High School and Move Out of Parental Home

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Abstract

Background—Emerging adults with diabetes are assuming diabetes care responsibility, graduating from high school and leaving their parental homes. We examined how diabetes care responsibility changed in relation to time (high school to post high school) and living situation (living independently or not of parents) and (2) the association of diabetes self-efficacy, worry about hypoglycemia, gender and glycemic control with these changes in responsibility among emerging adults with type 1 diabetes.

Methods—During the last 6 months in high school (T1), 113 participants completed Diabetes Care Responsibility (Total, Daily and Non-daily), Diabetes Self-Efficacy and Worry about Hypoglycemia scales. Participants again completed the responsibility scales post high school graduation (T2). We used a linear mixed effects model with diabetes self-efficacy, worry about hypoglycemia, time since graduation, living situation, gender and glycemic control as independent variables; and diabetes care responsibility (total, daily and non-daily) as dependent variables. Moderation involving diabetes self-efficacy, worry about hypoglycemia, gender, and glycemic control was also tested.

Findings—Diabetes care responsibility increased over time for total ($p < 0.001$), daily, ($p = 0.002$) and non-daily ($p < 0.001$); but the associations of self-efficacy and gender with diabetes care responsibility were moderated by living situation. Self-efficacy was negatively related to total ($p = 0.006$), daily ($p = 0.010$), and non-daily ($p = 0.030$) responsibility for those not living independently while positively related only to total responsibility ($p = 0.028$) for those living independently. Being female was positively related to total ($p = 0.007$) and non-daily ($p = 0.001$) responsibility for those living independently.

Conclusion—Diabetes care responsibility increased from high school to post high school among these emerging adults with diabetes. There is a complex relationship between self-efficacy, gender and responsibility related to living independently of parents for these youth.

Keywords

transitions; living arrangements; emerging adults; diabetes

Emerging adults with type 1 diabetes are assuming primary diabetes care responsibility (Wolpert, Anderson, & Weissberg-Benchell, 2009), graduating from high school (Aseltine & Gore, 1993) and leaving their parents' home (Furstenberg Jr., Rumbaut, & Settersten Jr., 2005). Living independently of parents occurs for up to 56% of emerging adults in general (Goldscheider, 1997; Arnett, 2003) and a similar portion (52%) of those with diabetes (Tebbi et al., 1990). When considering that many youth move in and out or parental homes (Arnett, 2000), even more (90%) of emerging adults live independently of parents for at least a 4-month period of time (de Marco & Berzin, 2008). Difficulties with these transitions place these young people's health at risk. Glycemic control, essential for decreasing serious health consequences of diabetes (Diabetes Control and Complications Trial Research Group, 1994), is known to be poor among 18 to 19 year olds with diabetes (Bryden et al., 2001; Insabella, et al., 2007).

These transitions are particularly important because assuming diabetes care responsibility is essential as emerging adults become more independent. Diabetes care responsibility is well known to increase over the adolescent years (Cameron et al., 2008; Hanna & Guthrie, 2003; Holmes et al., 2006; Ingerski et al., 2010; Ott et al., 2000; Palmer et al., 2004); to vary in degree of responsibility for different tasks (Anderson et al., 1990) and to involve several domains conceptualized as diabetes regimen, general health, and social presentation (Anderson et al; 1990); daily and non-daily management (Hanna & Guthrie, 2003); and direct or indirect management (Vesco et al., 2010). However, little is known about how responsibility, including certain aspects, changes for emerging adults as they graduate from high school and enter this developmental period of emerging adulthood (Arnett, 2007).

Assumption of diabetes care responsibility by youth is noted to be associated with their readiness (Hanna & Decker, 2010) and key personal characteristics may be particularly important as they become more independent and reliant on their own resources. A specific area of readiness for emerging adults is their diabetes self-efficacy; among adolescents, it is associated with more responsibility (Holmes et al., 2006) and mediates the relationship between responsibility and management (Ott et al., 2000). In contrast, low self efficacy reflects a lack of readiness because for adolescents with low self-efficacy, there was greater parent-adolescent sharing of responsibility (Helgeson et al., 2008; Iannotti et al., 2006) and better diabetes outcomes when parents were responsible (Palmer et al., 2009). Another area of readiness is worry about hypoglycemia because those with greater worry would be concerned about having ready access to parents who have provided assistance with hypoglycemic events. Up to 40% of children and adolescents in a given year are estimated to require assistance with hypoglycemia by another person (Aman, Karlsson, & Wranne, 1989; Limbert et al., 1993; Nordfeldt et al., 2003; Nordfeldt & Ludvigsson, 1997). Gender needs to be considered in relationship to these variables because females have greater maturity and self-reliance (Palmer et al., 2004; Pacaud et al., 2007) and hypoglycemic worries (Gonder-Frederick et al., 2006). In addition, diabetes control needs to be considered because greater responsibility is associated with poorer glycemic control among younger adolescents (Helgeson et al., 2008); however, it is not known if this relationship exists for the older age group of emerging adults.

Although little is known about these transitions for emerging adults with diabetes, these events are particularly important because assuming diabetes care responsibility is essential as they become more independent. Further, little information exists on the association of diabetes self-efficacy, worry about hypoglycemia, gender, and glycemic control with diabetes care responsibility among emerging adults with diabetes. Therefore, we examined (1) how diabetes care responsibility changed in relation to time (high school to post high school) and living situation (living independently or not of parents) and (2) the association of diabetes self-efficacy, worry about hypoglycemia, gender and glycemic control with changes in diabetes care responsibility among emerging adults with type 1 diabetes. Findings would provide insight for health care professionals preparing emerging adolescents during this transitional period and for those who plan to transition to independent living.

Methods

Design

This report utilizes data collected as part of a longitudinal study of the transition to young adulthood among youth with type 1 diabetes. The analyses used baseline data collected in the last 6 months of high school (T1) and follow-up data collected in the fall of the year, September through mid-December, post high school graduation (T2) for the first waves of recruitment (three consecutive years during the last 6 months of high school).

Procedure

Participants were enrolled if they were: 17 to 19 years of age; diagnosed with type 1 diabetes; able to speak and read English; in the last 6 months of high school; and living with an adult considered by participants to be their parent or guardian. Youth were excluded if they had a diagnosis of a serious psychiatric disorder or a second chronic illness that would interfere with becoming independent as judged by their health care provider. Of the 355 youth screened in the first three waves, 193 met eligibility criteria, 165 volunteered (85.5%) to be in the study and only 17 of the participants have dropped out of the study (10.3%).

The sample was recruited from outpatient diabetes care clinics at a regional university medical center, a private hospital and a regional diabetes center. Patients and their parents received a letter or recruitment flier from their primary diabetes physician. Youth were enrolled either face-to-face in the clinic or via telephone after they contacted study staff. The appropriate Institutional Review Boards provided approval. Consents (for those who were 18 years or older) or parental consents and youth assents (for those who were under 18 years of age) were obtained. Participants received incentives of $50 and $25 for completion of T1 and T2 data respectively.

Measures

Participants predominately completed Web-based forms; however, there was a paper and pencil option. At T1, socio-demographic and diabetes related information, diabetes care responsibility, diabetes self-efficacy and worry about hypoglycemia data were collected. Hemoglobin A1c as a measure of glycemic control was obtained from medical records and were dichotomized as good (< 7.5%) or not based on the ADA guidelines for youth (Silverstein et al., 2005). At T2, data were collected on living situation and again on diabetes care responsibility.

Diabetes Care Responsibility was measured by the Independent Functioning and Decision-making in Daily and Non-Daily Diabetes Management Checklists (Hanna & Guthrie, 2003). These checklists, developed for adolescents, were adapted from the Family Responsibility Questionnaire (Anderson et al., 1990) to measure daily and non-daily diabetes care

responsibilities. Examples of daily tasks were calculating insulin dose or bolus, deciding what food to eat when at home as well as when not, deciding when and how much to exercise. Examples of non-daily tasks were tracking and refilling supplies, making regular appointments, and deciding which health concerns to discuss at clinic visit. For this study, tasks where majority of emerging adults would be highly independent were deleted; such a task was w*ho checks and records glucose test results*. Participants were asked to respond about their degree of responsibility about specific tasks by noting if *parent alone (0), both adolescent and parent (1), or adolescent alone (2)* performed or made decision about it. The scores were summed; with potential scores ranging from 0–24 for the 12 items in the total, 0–8 for the 4 items in the daily, and 0–16 for the 8 items in non-daily responsibility. Higher scores indicated a higher degree of independence. Cronbach alpha coefficients for this sample were 0.64 for total, 0.33 for daily and 0.70 for non-daily responsibility scales. The low Cronbach alpha for daily responsibility scale was most likely influenced by the minimal variability in these tasks as participants were highly independent in them. Given that responsibility for daily diabetes care is essential for glycemic control, it was decided to keep daily diabetes care responsibility in the analysis.

The Diabetes-specific Self-efficacy Scale (Littlefield et al., 1992) measured youth's beliefs about their confidence in diabetes management abilities related to diet, glucose monitoring, insulin administration, and exercise. This scale was revised, adding an 8th item related to managing hypoglycemia. Participants were asked to grade themselves on how well they could perform tasks, ranging from an "A+" designating "*could not do better*" to an "F" designating "*you are a disaster*." The responses were summed for a total score that could range from 8–72. With this sample, the Cronbach alpha value was 0.85 for the 8-item scale.

Fear of Hypoglycemia Worries Subscale (Cox et al., 1987) measured 17 worries about hypoglycemia. Participants were asked to rate how often worries occurred from 1 (*never*) to 5 (*very often*). The responses were summed for total subscale scores with potential range of 18–90. With this sample, Cronbach alpha was 0.93 for the worry subscale.

Data Analysis

A linear mixed effects model was used to test the effect for selected socio-demographic and diabetes-related variables on changes in responsibility outcomes over T1and T2. Separate models were estimated for each of the outcome variables: total, daily, and non-daily diabetes care responsibility. An unstructured correlation matrix was specified to model covariance among the two repeated measures within each subject. Time was treated as a fixed effect. Moderation effects of time and living independently effects were tested by including relevant interaction terms. Effects tested within the initial full models are listed in Table 1. Non-statistically significant interaction effects were eliminated from the models. Statistically significant interaction effects were then followed up by simple main effects analyses (Keppel, 1991). All analyses were carried out using PROC MIXED in SAS/STAT software, using an α of 0.05.

Results

Sample

Participants included 113 emerging adults with type 1 diabetes who had complete data for the selected variables at T1 and T2. At T1, participants were, on average, 18.3 years of age (SD = 0.4); 94% were Caucasian; 58.4% were female; had an average HbA1c value of 8.5% (SD = 1.5; range = 6.1 =14); and on average, had been diagnosed with diabetes was 8.7 years (SD = 3.9; range = 1.1 – 17.2). Although all participants were living with at least one parent at T1 (inclusion criteria), by T2, 57% were living independently of their parents. At

T1, participants had relatively less than optimal level of total diabetes care responsibility; the mean of 13.4 was only slightly higher than the midpoint of the potential range of 0 to 24. However, on subscale analysis, participants had a high level of daily diabetes care responsibility (M = 7.3) that was close to the highest possible score (8) on this subscale and had a low to moderate level of nondaily diabetes care responsibility, with a mean of 6.2 on a subscale with a potential range of 0 to 16. Table 2 provides sample demographics and Table 3 describes distribution of diabetes care responsibility values.

Effects of Time since Graduation and Living Situation on Diabetes Care Responsibility

Table 4 lists main and statistically significant interaction effects for the dependent variables total (Model 1), daily (Model 2), and non-daily (Model 3) diabetes care responsibility. Simple main effects analysis results for final models are presented in Table 5.

Moderation of the diabetes self-efficacy effect by living independently was observed for total ($p < 0.001$), daily ($p = 0.009$), and non-daily ($p = 0.004$) responsibility (Table 4). Those results indicate that the slope of the association between diabetes self-efficacy and each of the dependent variables differed depending on whether the adolescent lived independently or not. Similarly, the interaction between female and living independently indicates that males and females responded differently to living independently in terms of total ($p = 0.011$) and non-daily ($p = 0.008$) responsibility.

Since neither time nor HbA1c were involved in interactions, main effects for those variables can be interpreted directly. Significant main effects for time indicate that values for total ($p < 0.001$), daily ($p = 0.002$), and non-daily ($p < 0.001$) responsibility increased (see Table 3) over time, even after controlling for other variables in the model. Finally, total, daily, and nondaily responsibility means were similar between HbA1c groups (all $p > 0.75$) after controlling for all other effects in the models.

Since all statistically significant interactions involved living independently, simple main effects analyses were performed separately for those living independently and those not living independently, and are presented in Table 5. Perhaps the most striking result involves diabetes self-efficacy. For participants who did not live independently, there was a significant inverse relationship between diabetes self-efficacy and total ($p = 0.006$), daily ($p = 0.010$), and non-daily ($p = 0.030$) responsibility. In contrast, participants who lived independently demonstrated an independent positive association between self-efficacy and total responsibility ($p = 0.028$) and no statistically significant independent association with daily ($p = 0.720$) and non-daily ($p = 0.081$) responsibility. Females living independently tended to have higher mean total ($p = 0.007$) and non-daily ($p=.001$) values than males. Mean total ($p = 0.424$) and non-daily ($p = 0.572$) values were similar for male and female participants who did not live independently.

Discussion

These emerging adults increased their diabetes care responsibility from pre-to-post high school. This is congruent with the increase in responsibility with age among adolescents (Cameron et al., 2008; Hanna & Guthrie, 2003; Holmes et al., 2006; Ingerski et al., 2010; Ott et al., 2000; Palmer et al., 2004). Importantly, these youth, while in high school and post, have high levels of responsibility for daily diabetes tasks, essential for maintenance of glycemic control. Out of a potential score of 8, they had average scores of 7.3 during high school and 7.5 post high school. These youth are also assuming more responsibility for non-daily tasks such as refilling their supplies and making appointments. It appears that these emerging adults are moving toward meeting expectations held for them (Wolpert et al., 2009). However, there is still room for improvement with relatively low levels of non-daily

responsibility. The average non-daily responsibility scores were 6.2 during high school and 8.7 post, indicating low to moderate levels of responsibility based on the scale midpoint of 8.0. These youth may still be relying on parents for these non-daily tasks. This is congruent with the process of becoming responsible for diabetes care that involves receiving support from parents (Karlsson, Arman & Wikblad, 2008). It is difficult to compare these youth to other samples of emerging adults with diabetes; this group has been understudied. In addition, it is difficult to compare to adults with diabetes; responsibility, conceptualized as independence for youth, is not measured with adults since they are assumed to have met this developmental task of full responsibility.

For these emerging adults, diabetes care responsibility has a complex relationship with living situation, moderated by diabetes self-efficacy and gender but not with worry about hypoglycemia and glycemic control. Low self-efficacy was associated with greater total, daily and non-daily responsibility for youth remaining at home post high school graduation while for those who lived independently, greater self-efficacy was associated with greater responsibility. Youth remaining in parental homes may have a low level of readiness for this transition. This could reflect an ongoing pattern established in earlier adolescence where responsibility combined with low level of readiness is associated with poor diabetes outcomes (Palmer et al., 2009; Palmer et al., 2004; Wysocki et al., 1996). In addition, females living independently tended to have higher total and non-daily responsibility compared to males. While this is consistent with findings that females have greater responsibility than males (Pacuad et al., 2007), differences were found only in females living independently in this sample. Contrary to our speculations, worry about hypoglycemia was not associated with emerging adults' responsibility and living situation. Finally, glycemic control was not associated with diabetes responsibility which is in conflict with the association with younger age groups (Helgeson et al., 2008).

Limitations of the study need to be considered. The sample was typical of youth with type 1 diabetes nationally in ethnicity and similar to the portion of emerging adults with diabetes living independently of parents in the one known published study (Tebbi et al., 1990). Howevr, the sample is under-represented in terms of those from lower socioeconomic levels; only 2% of mothers and 7% of fathers had less than a high school education and only 9% of families did not have enough money. In addition, the sample is likely not representative of all youth with type 1 diabetes because those with serious co-morbid conditions were excluded. However, only 20.4% of the sample had good glycemic control (HbA1c < 7.5%) and thus reflects typical youth who struggle with diabetes control (Silverstein et al., 2005). Another limitation is the low reliability of the daily responsibility subscale; this was likely due to the high degree of independence (and low variability) that emerging adults already have in this area. Finally, the sample size limited our ability to examine the complex relationship of time, living independently of parents, diabetes self-efficacy and diabetes care responsibility with health outcomes of diabetes management and glycemic control.

Based upon the findings, there are practice and research implications. Health care professionals can prepare these youth for the transition to young adulthood by focusing on areas in need of improvement; such areas are non-daily diabetes responsibilities such as tracking and refilling supplies as well as communicating with health care professionals, teachers and friends about their diabetes. In addition, health care professionals can focus on improving diabetes care responsibility in conjunction with diabetes self-efficacy prior to moving out of parental homes. While in a parental supportive environment, success with diabetes care responsibility would be more likely and youth would have greater self-efficacy. Further longitudinal analysis with a larger sample is advocated; this would enable examination of how transitional events, diabetes self-efficacy, and diabetes care

responsibility influence diabetes management and future glycemic control during emerging adulthood.

- These youth have high levels of diabetes care responsibility essential for maintenance of glycemic control.
- These youth, with relatively low to moderate levels of non-daily responsibility, may still be relying on parents for tasks such as tracking and refilling supplies.
- Low diabetes self-efficacy may be an indication of low readiness for these youth to move out of parental homes.
- Health care professionals are advocated to work with youth and their parents in the transfer of responsibility for non-daily diabetes care in preparation for adulthood.
- Health care professionals are advocated to work with youth and their parents on improving diabetes care responsibility in conjunction with diabetes self-efficacy prior to moving out of parental homes.

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Table 1

Listing of effects tested for each dependent variable in initial full linear mixed models.

Intercept
Time
Living Independently
Diabetes Self Efficacy
Worry about Hypoglycemia
Female
Hgba1c < 7.5%
Time*Living Independently
Time*Diabetes Self Efficacy
Time*Worry about Hypoglycemia
Time*Female
Time*Hgba1c < 7.5%
Living Independently*Diabetes Self Efficacy
Living Independently*Worry about Hypoglycemia
Living Independently*Female
Living Independently*Hgba1c < 7.5%

Table 2

Sample characteristics of emerging adults (N = 113).

Variables Measured at T1	
Gender (n)	113
Female (%)	58.4
Male (%)	41.6
Race (n)	113
Black (%)	5.3
White (%)	93.8
Other (%)	0.9
Insulin Administration (n)	113
Injection (%)	52.2
Pump (%)	47.8
Living Situation (n)	113
Only mother or only father (%)	15.9
Both mother/father in same house (%)	58.4
Father and step-mother (%)	2.7
Mother and step-father (%)	14.2
Other (%)	8.8
Mother's Education (n)	112
< High school (%)	1.8
High school degree (%)	44.6
Associate or vocation degree (%)	17.9
4 yr college degree (%)	22.3
Master's degree or higher (%)	13.4
Father’s Education (n)	110
< High school (%)	7.3
High school degree (%)	43.6
Associate or vocation degree (%)	5.5
4 yr college degree (%)	26.4
Master’ degree or higher (%)	17.3
Family Income (n)	109
Not enough (%)	9.2
Just enough (%)	65.1
More than enough (%)	25.7
Variables Measured at T2	
Live Independently of Parental Home (n)	113
Not independent (%)	43.4

Variables Measured at T1	
Independent (%)	56.6
Enrolled in College (n)	113
Enrolled in college (%)	78.8
Not enrolled in college (%)	21.2

Table 3

Means and standard deviations for diabetes care responsibility outcomes: 1) total, 2) daily, and 3) non-daily.

Variable	Total Sample (n=113)	Not Living Independently of Parents (n=49)	Living Independently of Parents (n=64)
T1: In High School			
Total Diabetes Care Responsibility	13.4 (2.8)	13.6 (3.0)	13.3 (2.7)
Daily Diabetes Care Responsibility	7.3 (0.9)	7.3 (0.9)	7.2 (0.9)
Non-daily Diabetes Care Responsibility	6.2 (2.5)	6.4 (2.7)	6.1 (2.4)
T2: Post High School			
Total Diabetes Care Responsibility	16.2 (3.9)	16.1 (4.1)	16.2 (3.7)
Daily Diabetes Care Responsibility	7.5 (0.7)	7.5 (0.8)	7.6 (0.6)
Non-daily Diabetes Care Responsibility	8.7 (3.6)	8.6 (3.7)	8.7 (3.6)

Table 4

ANOVA Tables for final linear mixed models examined, including statistically significant interactions.

Effect	F	P
Model 1: Total Diabetes Care Responsibility[1]		
Time	94.8	<0.001
Living Independently	17.4	<0.001
Diabetes Self Efficacy	9.4	0.003
Worry about Hypoglycemia	1.5	0.219
Female	0.9	0.346
Hgba1c < 7.5%	0.1	0.752
Living Independently*Diabetes Self Efficacy	14.0	<0.001
Living Independently*Female	6.7	0.011
Model 2: Daily Diabetes Care Responsibility[2]		
Time	9.8	0.002
Living Independently	5.8	0.017
Diabetes Self Efficacy	8.8	0.004
Worry about Hypoglycemia	0.1	0.764
Female	2.1	0.154
Hgba1c < 7.5%	0.1	0.776
Living Independently*Diabetes Self Efficacy	7.0	0.009
Model 3: Non-daily Diabetes Care Responsibility[1]		
Time	99.1	<0.001
Living Independently	12.0	<0.001
Diabetes Self Efficacy	5.4	0.022
Worry about Hypoglycemia	1.9	0.168
Female	0.5	0.493
Hgba1c < 7.5%	0.0	0.933
Living Independently*Diabetes Self Efficacy	8.5	0.004
Living Independently*Female	7.3	0.008

[1] Degrees of freedom for F statistic are 1, 105

[2] Degrees of freedom for F statistic are 1, 106

Table 5

Unstandardized coefficients (Beta) and corresponding standard errors (SE) from simple main effects mixed linear models stratified by independent living status.

	Did not live independent of parents (n=49)		Lived independent of parents (n=64)	
Independent variable	**Beta (SE)**	**p-value**	**Beta (SE)**	**p-value**
Model 1: Total Diabetes Care Responsibility				
Intercept	19.57 (2.64)	<.001	7.25 (1.96)	<.001
Time (post high school vs. high school)	2.43 (0.45)	<.001	2.95 (0.35)	<.001
Diabetes Self efficacy	**−0.12 (0.04)**	**.006**	**0.06 (0.03)**	**.028**
Worry about Hypoglycemia	0.01 (0.03)	.663	0.04 (0.03)	.173
Female	**−0.67 (0.83)**	**.424**	**1.83 (0.66)**	**.007**
Hgba1c<7.5%	−0.29 (0.95)	.763	−0.16 (0.78)	.835
Model 2: Daily Diabetes Care Responsibility				
Intercept	9.18 (0.66)	<.001	7.02 (0.49)	<.001
Time (post high school vs. high school)	0.18 (0.11)	.115	0.31 (0.11)	.008
Diabetes Self efficacy	**−0.03 (0.01)**	**.010**	**0.002 (0.01)**	**.720**
Worry about Hypoglycemia	−0.01 (0.01)	.231	0.01 (0.01)	.439
Female	−0.19 (0.21)	.366	−0.26 (0.16)	.118
Hgba1c<7.5%	−0.38 (0.24)	.116	0.31 (0.19)	.1105
Model 3: Non-daily Diabetes Care Responsibility				
Intercept	10.03 (2.45)	<.001	1.40 (1.71)	.417
Time (post high school vs. high school)	2.24 (0.40)	<.001	2.60 (0.30)	<.001
Diabetes Self efficacy	**−0.08 (0.04)**	**.030**	**0.04 (0.02)**	**.081**
Worry about Hypoglycemia	−0.02 (0.03)	.413	0.03 (0.03)	.258
Female	**−0.44 (0.77)**	**0.572**	**1.99 (0.58)**	**.001**
Hgba1c<7.5%	0.32 (0.88)	0.724	−0.30 (0.70)	.665

Note. Variables with a significant interaction with living independently of parents are bolded.