Published in final edited form as:
Res Nurs Health. 2014 October ; 37(5): 399–408. doi:10.1002/nur.21620.

Diabetes-related Quality of Life and the Demands and Burdens of Diabetes Care among Emerging Adults with Type 1 Diabetes in the Year after High School Graduation

Kathleen M. Hanna,
Carol M Wilson Endowed Chair, College of Nursing, University of Nebraska Medical Center, 985330 Nebraska Medical Center, Omaha, NE 68198-5330

Michael T. Weaver,
Indiana University School of Nursing, James E. Slaven, Department of Biostatistics, Indiana University School of Medicine

J. Dennis Fortenberry, and
Indiana University School of Medicine

Linda A. DiMeglio
Indiana University School of Medicine

Kathleen M. Hanna: kathy.hanna@unmc.edu

Abstract

The roles of glycemic control, diabetes management, diabetes care responsibility, living independently of parents, and time since high school graduation in predicting diabetes-related quality of life (DQOL) were examined in 184 emerging adults with type 1 diabetes. Data were collected at graduation and one year later. Analyses controlling for selected covariates were completed using generalized linear mixed models. Better diabetes management was associated with more positive responses on all four dimensions of DQOL. Impact and worry of DQOL were greater in the presence of depressive symptoms, and life satisfaction was lower. DQOL life satisfaction was lower in those living independently of parents. Young women reported lower diabetes-related health status than did young men. Time since graduation was not linked to DQOL. Further research is needed on ways to improve DQOL in conjunction with diabetes management and on ways that families can support DQOL when youth live independently.

Keywords

Diabetes-related quality of life; emerging adults; adolescence; diabetes; self-care; self-management

Emerging adulthood, defined as 18 to 25 years of age (Arnett, 2007), is a critical period for psychosocial adaptation in the transition to adulthood (Aseltine & Gore, 1993) and may be a critical period for diabetes-related quality of life (DQOL; Ingerski, Laffel, Drotar, Repaske, & Hood, 2010). Glycemic control often worsens during this period (Bryden et al., 2001; Insabella, Grey, Knafl, & Tamborlane, 2007), and the demands and burdens of diabetes care are particularly challenging during this developmental stage (Jacobson, 1996).

During emerging adulthood, youth become independent in their lives in general (Arnett, 2007), often moving to living independently (Furstenberg Jr., Rumbaut, & Settersten Jr., 2005). Similarly, they become independent in diabetes management (Schilling, Knafl, & Grey, 2006) and take on primary responsibility for their diabetes care (Hanna, Weaver, Stump, Dimeglio, et al., 2013). The year following high school (HS) graduation may be especially important because this graduation is a major rite of passage (Delaney, 1995) and the year afterward has long been known as a critical time for adaptation (Aseltine & Gore, 1993).

Little is known, however, about how the demands and burdens of diabetes care during emerging adulthood affect quality of life with diabetes. Therefore, the purpose of this study was to examine the associations of DQOL with the demands and burdens of diabetes care (glycemic control, diabetes management, diabetes care responsibility, and living independently of parents) among early emerging adults with type 1 diabetes during the year after high school graduation. Health care professionals working with these youth may benefit from an increased understanding of the impact of demands and burdens of diabetes care during this time period.

Conceptual Framework

This study was guided byHanna's (2012) conceptual framework on the emerging adulthood transition for youth with type 1 diabetes, built on theory of transitions (Meleis, 2010), in which Hanna posited that the many changes experienced in the transitional period of emerging adulthood require adaptation to new roles and responsibilities (Arnett, 2007; Furstenberg Jr. et al., 2005). Although this developmental period is known for new freedoms and delayed responsibilities (Arnett, 2007), these may not be perceived as a luxury by youth who are expected to assume responsibility for their diabetes care (Wolpert, Anderson, & Weissberg-Benchell, 2009). This developmental period also is characterized by instability, and the common transitional event of moving out of the parental home (Arnett, 2007; Furstenberg Jr. et al., 2005) may have implications for diabetes care.

An indicator of success or difficulty experienced in making such transitions is the level of one's sense of well-being (Meleis, 2010). For emerging adults with diabetes, the health outcome of DQOL serves as an indicator of transition success (Hanna, 2012). Health-related quality of life is defined as the impact on one's life of the disease condition and its treatment (Ferrans, Zerwic, Wilbur, & Larson, 2005; Wilson & Cleary, 1995). In this study, the concept of quality of life specific to type 1 diabetes was conceptualized as having four dimensions commonly measured in diabetes: the impact of diabetes on life in general, worries about diabetes, satisfaction with life, and perceived health status (Ingersoll & Marrero, 1991).

Correlates of Diabetes-related Quality of Life

DQOL is proposed to be associated with glycemic control, managing one's diabetes regimen, and assuming the role of primary responsibility for diabetes care. Better glycemic control is assumed to be associated with better DQOL because such control reduces the risk of serious long-term health consequences from diabetes (Diabetes Control and

Complications Trial Research Group, 1994), so those with better glycemic control may worry less about the disease. Little is known on DQOL among emerging adults, but in samples of children, adolescents, and young adults, those with better glycemic control had higher perceived health status (Huang, Palta, Allen, LeCaire, & D'Alessio, 2004; Ingersoll & Marrero, 1991).

However, it is not clear whether glycemic control is associated with the psychosocial dimensions of quality of life. Some investigators of adolescents have reported no association (Faulkner, 2003; Graue, Wentzel-Larsen, Hanestad, Batsvik, & Sovik, 2003; Ingersoll & Marrero, 1991), but others have reported a positive association between DQOL and glycemic control (Hanberger, Ludvigsson, & Nordfeldt, 2009; Hassan, Loar, Anderson, & Heptulla, 2006; Hoey et al., 2001; Ingerski et al., 2010; Nansel et al., 2008). The wide age range of youth in these studies may have contributed to the conflicting findings. In the emerging adulthood years, when glycemic control worsens for many of these youth (Bryden et al., 2001; Insabella et al., 2007), those attempting to improve their control may perceive greater burden of the demands of diabetes care and hence report poorer DQOL.

Emerging adults' DQOL is also likely associated with the demands and burdens of diabetes management and taking on primary responsibility for diabetes care, conceptualized in this study as two separate constructs. Diabetes management refers to behaviors related to one's diabetes regimen (Hanna, 2012). Responsibility for diabetes care reflects the degree of autonomy in performing those behaviors and making decisions (Hanna & Decker, 2010).

Emerging adults had less than ideal diabetes management after HS graduation (Hanna, Weaver, Stump, Slaven, et al., 2013). Diabetes management may be worse when the care regimen is perceived as burdensome and demanding, and in turn DQOL would be perceived as lower. Associations between DQOL and diabetes management among school-aged children and adolescents have not been consistent, with results of one study showing higher levels of DQOL associated with better management among 9- to 16-year-olds (Nansel et al., 2008) and another showing no association among 10- to 18-year-olds (Faulkner & Chang, 2007). These conflicting findings for younger samples may be related to the wide age ranges and differences in the presumed underlying degrees of independence.

Emerging adults are taking on primary responsibility for daily diabetes care and are increasing their responsibility for non-daily diabetes care as well (Hanna, Weaver, Stump, Dimeglio, et al., 2013). Qualitative evidence suggests that responsibility for diabetes care is perceived as demanding and burdensome (Hanna & Guthrie, 2000) and thus may be negatively associated with DQOL in emerging adulthood.

DQOL is also proposed to be affected by increasing independence and transitional events (Hanna, 2012). In emerging adulthood, youth move from childhood dependence to adult independence (Côté & Bynner, 2008) and are exploring future possibilities (Arnett, 2007). For youth with diabetes, such independence may bring more worries about and a greater impact of diabetes on their lives. Further, the demands and burdens of diabetes care may limit the perception of future possibilities, which may decrease satisfaction with life. Whether the changes of older adolescence worsen DQOL is unclear. In studies including

wide age ranges of children and adolescents, some DQOL components had no relationship to age (Faulkner, 2003; Hoey et al., 2001) or were associated with age only in older youth (Faulkner, 2003). In others, older youth had better DQOL than younger youth (Graue, Wentzel-Larsen, Hanestad, & Sovik, 2005; Lawrence et al., 2012). In one longitudinal study of a cohort of youth from adolescence to emerging adulthood, no change in DQOL was reported (Insabella et al., 2007). However, these investigators did focus on the year after HS graduation or on the second major transitional event, moving out of the parental home (Furstenberg Jr. et al., 2005). Other major life events have been associated with DQOL among adolescents (Helgeson, Escobar, Siminerio, & Becker, 2010). Thus, it would be important to examine relationships among these variables in the year after high school graduation.

Selected individual characteristics associated with health-related quality of life in general (Ferrans et al., 2005; Wilson & Cleary, 1995) may also be associated with DQOL in emerging adults with diabetes (Hanna, 2012). Depressive symptoms are associated with lower levels of DQOL among children, adolescents, and emerging adults with diabetes (Hassan et al., 2006; Ingerski et al., 2010; Lawrence et al., 2012; Nansel et al., 2008). Gender also may influence DQOL, though findings have not been consistent. Female children and adolescents had lower DQOL than did males in some studies (Hanberger et al., 2009; Huang et al., 2004; Ingersoll & Marrero, 1991; Lawrence et al., 2012), but there was no association between gender and longitudinal change in DQOL from adolescence to emerging adulthood (Insabella et al., 2007).

The association of DQOL with the demands and burdens of diabetes care may be tempered by diabetes-related factors. The length of time one has lived with diabetes may affect perceived burden. However, DQOL was inversely associated with disease duration in two studies (Huang et al., 2004; Ingerski et al., 2010), positively associated with duration in another (Ingersoll & Marrero, 1991), and had no relationship with disease duration in two others (Faulkner & Chang, 2007; Pereira, Berg-Cross, Almeida, & Machado, 2008). Whether insulin is administered via multiple injections or via continuous subcutaneous insulin infusion (CSII) also may influence perceived disease burden and DQOL, although evidence on the association of CSII with quality of life among youth with type 1 diabetes was conflicting in one systematic review (Barnard, Lloyd, & Skinner, 2007).

To clarify these relationships and address these gaps in the literature, a longitudinal analysis of the demands and burdens of diabetes care in relation to DQOL in youth during the year after HS graduation was designed to examine the association of DQOL (impact, worry, satisfaction, and health status) with the predictors of glycemic control, diabetes management, primary diabetes care responsibility, time since graduation, and living independently of parents, while controlling for selected baseline (gender, depressive symptoms, and time since diabetes diagnosis) and time-varying (insulin administration method) covariates.

Methods

Design

Data were obtained as part of a larger longitudinal study described elsewhere (Hanna, Weaver, Stump, Dimeglio, et al., 2013; Hanna, Weaver, Stump, Slaven, et al., 2013; Hanna, Weaver, Stump, Fortenberry, & DiMeglio, 2014). The analysis reported here was limited to the period from HS graduation to 12 months after graduation.

Sampling Procedure

Following IRB approval, participants were recruited from outpatient diabetes care clinics at a university medical center, a private hospital, and a private diabetes clinic. Health care providers gave a brief study summary. Interested youth (17 - 19 years old and in the last 6 months of high school) were screened for eligibility criteria: type 1 diabetes for at least 1 year; able to read and speak English; and living with their parent or guardian. Youth were excluded if they had a serious psychiatric disorder or a second chronic illness that could interfere with becoming independent. More females than males agreed to participate ($p <$. 05); however, there were no differences in either age or race between those who participated and those who did not.

Consent was obtained from youth 18 years old or older, and parental permission along with youth assent were obtained for youth under 18. At the time of baseline data collection, there was a 91% participation rate of those initially enrolled; 16 did not complete baseline data collection after consent, 2 requested to be withdrawn, and staff were not able to contact 2 after consent. During longitudinal data collection in the parent study, most participants (97%) were retained. Participants not retained consisted of three who requested to be withdrawn, two who died, and two who were lost to contact and did not complete questionnaires after 6- or 9-month data points. Those who missed some but not all data collection points were retained in the sample.

Data Collection

Participants completed questionnaires on other variables either via a web-based system or via paper and pencil. In addition to measures described below, diabetes-related and socio-demographic data were obtained via self-report (gender and insulin administration method) or medical records (date of diabetes diagnosis).

Time 1 (T1) data for this analysis were collected within 3 months of HS graduation, and Time 2 (T2) data were collected approximately 12 months after HS graduation. Data on depressive symptoms, considered a relatively stable trait (Cole & Martin, 2005), were collected at baseline enrollment into the study. DQOL, glycemic control, diabetes management, diabetes care responsibility, and insulin administration method were collected at both T1 and T2.

Measures

DQOL—Diabetes-related quality of life was assessed by Ingersoll and Marrero's (1991) Modified Quality-of-Life Measure for Youths. The measure includes subscales for life

satisfaction (17 items), disease impact (23 items), and disease-related worries (11 items), as well as a 1-item rating of health. Some items were revised to reflect emerging adults' lives; for example, a work situation was included along with the school situation in the original instrument.

Items targeted how often diabetes currently affected their lives and how often they worried about their diabetes, scored from *never* (1) to *all the time* (5), as well as the degree to which they were satisfied with life, scored from *very satisfied* (1) to *very unsatisfied* (5). Satisfaction items were recoded so that higher scores reflected greater satisfaction. For the 1-item rating of health, participants were asked to rate their health as *poor* (1), *fair* (2), *good* (3), or *excellent* (4).

Responses were summed, with potential ranges of 17-85, 23-115, and 11-55 in the satisfaction, impact, and worry subscales, respectively, with higher scores indicating higher levels of the variable. Cronbach alpha coefficients for the Impact, Worries, and Life Satisfaction subscales were .84, .83, and .90 at T1; and .85, .84, and .90 at T2, respectively.

Glycemic control—HbA1c test results were obtained from medical records. Bias-adjusted HbA1c values were calculated by subtracting the assay-specific bias value established by College of American Pathologists (2012) from the reported HbA1c value.

Diabetes management—This variable was measured with the 24-item Emerging Adult Diabetes Management Self-Report. This measure was adapted for this study from the interview format of the Diabetes Self-Management Profile (Harris et al., 2000) to a self-completion format. Participants were asked to respond to how often they performed diet, exercise, blood glucose testing, insulin administration, and hypoglycemia tasks and how often they made changes in them. The responses were summed for a total score (0 - 84 range), with higher scores signifying better management behavior. The Cronbach alpha coefficient was .81 at T1 and .85 at T2.

Primary diabetes care responsibility—This variable was measured by a revised version of the Independent Functioning and Decision-making in Daily and Non-Daily Diabetes Management Checklist (Hanna & Guthrie, 2003). To adapt the measure to emerging adults, MD and PhD experts in diabetes and youth deleted the checklist items for which emerging adults were expected to be highly independent, such as checking glucose test results, and retained items that might or might not be performed by emerging adults, such as making health care appointments.

Participants were asked whether *parent alone*, *both youth and parent*, or *youth alone* performed or made decisions about 12 specific tasks. A score for percentage of primary diabetes responsibilities performed by the youth independently was calculated by summing the number of items for which the youth alone performed tasks or made decisions about diabetes care and then dividing by the total number of items.

Living independently of parents—This variable was measured every 3 months. Participants were asked about with whom they were living (mother, father, both parents,

step-parent, friends, college roommate, boyfriend or girlfriend, alone, or other). Their responses were categorized as living independently of parents or not.

Covariates

Depressive symptoms were measured by the Beck Depression Inventory-Second Edition (Beck, Steer, & Brown, 1996). On a scale from 0 to 3, participants rated their experience of depressive symptoms. The responses were summed, with scores of 14-19 considered to be mild, 20-28 moderate, and 29-63 severe. The Cronbach alpha coefficient was .92. The scores were dichotomized as presence of depressive symptoms (score of 14 or greater) or not (scores 0-13) because this sample had low levels of self-reported depressive symptoms. Gender, insulin administration method, and date of diabetes diagnosis were identified by self-report or collected from medical records.

Data Analyses

Generalized linear mixed models (GLMM) methods were used to examine the associations between each of the four DQOL dimensions (impact, worry, satisfaction, and health status) and each of the main predictors (glycemic control, diabetes management, diabetes care responsibility, time [T1 and T2]), and living independently of parents, after controlling for selected covariates (gender, duration of diabetes diagnosis, type of insulin administration, and depressive symptoms). The GLMM approach enabled us to take into account the dependence of the repeated measures, use all observations, control for possible confounding variables, and incorporate time-varying variables where applicable, and to retain all participants despite some missing data. Statistical analyses were performed using SAS v9.3 (SAS Institute, Cary, NC).

All analytic assumptions were tested. Collinearity was examined by analyzing variance inflation factors (VIF; Belsley, Kuh, & Welsch, 1980). The highest VIF value was 1.57. Collinearity between explanatory variables would have been considered high if VIF values were 5 or greater (Kutner, Nachsheim & Neter, 2004). Interactions between time and all variables in the model were tested, with final models retaining those interactions that were statistically significant. Covariance structures were tested, and the one with the best fit according to Bayesian information criteria was used.

Results

Sample Characteristics

At baseline, the 184 HS graduates with type 1 diabetes were 18.2 years of age (*SD* = 0.44) on average; most were white (93.5%); and y had lived with diabetes for 8.5 years (*SD* = 3.96) and had an adjusted HbA1c of 8.9% (*SD* = 1.7). They were about equally divided between administering insulin via CSII (48%) or multiple daily injections (52%). Only a few (*n* = 24; 13%) met the criterion of having depressive symptoms (mild or greater). Slightly over half were female (56.5%). Most of the youth came from families whose parents were married (64%). Ninety-six percent of both their mothers and fathers had a HS education or greater.

Descriptive Statistics

Table 1 provides descriptive statistics for the four DQOL outcomes and for predictors and covariates. Data on the main outcome variable measure of DQOL at T2 were available for 161 (88%) youth in the sample. Overall, the scores for the four dimensions of DQOL reflected relatively good quality of life. The average diabetes impact score at both baseline and at follow-up was considerably below 69, the midpoint of the potential range of scores, indicating a relatively low perceived impact on participants' lives. Likewise, the average diabetes-related worry scores at baseline and at follow-up were considerably below 33, the midpoint of the potential range of scores, again indicating a relatively low level of worry. The average satisfaction with life scores at baseline and at follow-up were both well above 51, the midpoint of the potential ranges of scores, although they were considerably below 85, the highest potential score. These scores indicate moderate levels of life satisfaction. The average self-reported health status at baseline and at follow-up indicated fair to good health. All participants, as HS seniors, were living at home when enrolled in the study, but 9% were living independently of parents at graduation and 59% were living independently by 12 months after graduation.

Association of DQOL Outcomes with Predictors

Table 2 shows results from the final GLMM analysis for each of the four DQOL outcome variables. None of the interaction effects examined were statistically significant and so none were included in the models. There was no independent association between Time and any of the outcome variables, indicating that, after controlling for all other variables in the model, outcome values were relatively stable over time.

Associations with DQOL: Impact—Diabetes impact was independently associated with diabetes management and with depressive symptoms. DQOL Impact scores were negatively related to diabetes management and positively related to presence of depressive symptoms (BDI > 14).

Associations with DQOL: Worry—Diabetes-related worry was independently associated with diabetes management scores and with depressive symptoms. DQOL Worry scores were negatively related to diabetes management and positively related to presence of depressive symptoms.

Associations with DQOL: Satisfaction—Diabetes-related life satisfaction was independently associated with diabetes management, with living independently of parents, and with presence of depressive symptoms. DQOL life satisfaction was negatively related to living independently of parents and depressive symptoms and positively related to diabetes management.

Associations with DQOL: Health Status—Self-reported health status was independently associated with diabetes management and with gender. DQOL perceived health status was positively correlated with diabetes management. Female participants reported worse diabetes-related health status.

Discussion

The findings of this study contribute evidence that emerging adults with diabetes have relatively good diabetes-related quality of life despite being in a critical period of adaptation. Emerging adults, as they graduated from high school and during the following year, reported that diabetes had only a relatively minor impact on their lives, they had minimal worries about their diabetes, they were moderately satisfied with their lives, and their health status was fair to good. These findings are consistent with findings by others (Insabella et al., 2007), who reported DQOL to be relatively good among adolescents and emerging adults with type 1 diabetes.

DQOL remained relatively stable during this period, suggesting that high school graduation, a major rite of passage (Delaney 1995), was not associated with changes in DQOL. The stability of DQOL during the year after graduation is consistent with the finding on the relative stability of QOL for the general population of youth after graduation (Gillison, Skevington, & Standage, 2008) and the relative stability of DQOL over a 5-year period from adolescence to emerging adulthood (Insabella et al., 2007).

Importantly, the findings of this study are evidence that, in early emerging adults during the first year after high school, the demands and burdens of diabetes care did not appear to be detrimentally associated with diabetes-related quality of life. This result contrasts with the long-held premise that diabetes care interferes with the quality of life for youth (Jacobson, 1996).

First, our expectation that the demands and burdens of maintaining glycemic control would be associated with lower diabetes quality of life was not supported. Glycemic control was not independently associated with any aspect of DQOL among these emerging adults, challenging existing evidence that poor glycemic control leads to poor perceived health status as a component of DQOL (Huang et al., 2004; Ingersoll & Marrero, 1991). These youth may not have seen their health as poor because at that point they had few long-term health complications of diabetes (Peters, Laffel, & American Diabetes Association Transitions Working, 2011). The sample did, however, have relatively poor glycemic control, but limited variability in their HbA1c may have reduced our ability to detect an association with perceived health status. In addition, glycemic control was not independently associated with the impact of diabetes on life, worry about diabetes, or satisfaction with life in general.

The findings thus add to the conflicting evidence regarding the association of glycemic control with these psychosocial dimensions of DQOL, as the literature includes some evidence of no association (Faulkner, 2003; Graue et al., 2003; Ingersoll & Marrero, 1991) and of a positive relationship (Hanberger et al., 2009; Hassan et al., 2006; Hoey et al., 2001; Ingerski et al., 2010; Nansel et al., 2008). Inconsistent findings may reflect the increasing freedom of emerging adulthood (Arnett, 2007), which may take precedence over health matters.

Second, our expectation that there would be an inverse relationship between the demands and burdens of assuming more primary responsibility for diabetes care and diabetes quality

of life was not supported. More diabetes care responsibility was not associated with greater impact of diabetes on their lives, more worry about their diabetes, less satisfaction with their lives, or poorer reported health. Although these youth were increasing their self-care responsibility for both daily and non-daily diabetes care (Hanna, Weaver, Stump, Dimeglio, et al., 2013), these tasks were not seen as burdensome and demanding, as was the case with adolescents (Hanna & Guthrie, 2000). On average, these youth had lived with the diabetes diagnosis for around 9 years and they had likely been gradually assuming primary responsibility for their diabetes over these years.

Our expectation that diabetes management would be associated with DQOL was supported, but not in the expected negative direction. When youth in this study had better diabetes management, they reported that the condition had less impact on their lives, they worried less about their diabetes, they were more satisfied with their lives, and they reported better health. It is possible that these more cognitively mature youth, with the ability to think hypothetically (Steinberg, 2008), would be more likely to perceive higher levels of management behaviors as reducing the likelihood of diabetes consequences, and thus perceive less worry about and less impact of diabetes as well as more satisfaction with life and better health. Different management styles have been documented among adolescents (Schneider et al., 2007). Those who better managed their diabetes may not have perceived the requirements of the diabetes regimen as difficult. Conversely, those who perceived a higher DQOL may not have perceived their diabetes regimen as demanding and burdensome and therefore better managed their diabetes. Further research is needed on the complex relationship of diabetes management and diabetes quality of life.

Consistent with our expectation that these transitioning youth would assume most of the burden for their diabetes care, those living independently of parents during the year after high school graduation tended to rate diabetes quality of life, specifically satisfaction with life, as lower than those who did not live independently of parents. This is an interesting finding, in that available technology makes it possible for parents to remain involved and shoulder some of the demands and burdens of their sons' and daughters' diabetes management via texting. It could also be speculated that these youth see their financial reliance on their parents, specifically around the costs of diabetes care, as counter to their aspirations for independence. Continuing financial reliance on parents is now an attribute of emerging adulthood in general (Côté & Bynner, 2008). Thus, family co-management needs to be further researched in this population.

Depressive symptoms and gender were independently associated with DQOL. Youth with depressive symptoms had higher worry about diabetes and lower life satisfaction, but they perceived their health as no poorer than did those without depressive symptoms. These findings are consistent with those of other studies suggesting that diabetes-related quality of life is associated with depressive symptoms (Hassan et al., 2006; Ingerski et al., 2010; Nansel et al., 2008). In this study, females had poorer perceived health than males, but not lower levels of psychosocial quality of life in terms of disease impact, worry about disease, or satisfaction with life. This is only partially consistent with existing findings that females have lower levels of DQOL than males (Hanberger et al., 2009; Huang et al., 2004; Ingersoll & Marrero, 1991).

Time with diabetes and method of insulin administration were not independently associated with any aspect of diabetes-related quality of life. Lack of association of time with diabetes and DQOL is consistent with the mixed findings in other samples (Faulkner & Chang, 2007; Huang et al., 2004; Ingerski et al., 2010; Ingersoll & Marrero, 1991; Pereira et al., 2008). Similarly, the finding that insulin administration method was not independently associated with DQOL reflects others' mixed findings (Barnard et al., 2007). The conflicting findings may reflect issues with measurement and differences in modeling approaches across studies.

Limitations on external validity need to be considered. The results of this study can only be generalized to other samples of early emerging adults with type 1 diabetes who have graduated from high school, are predominately white, and are from families in which most parents are married and high school graduates. In several ways, this sample was typical of those in their age group. Emerging adults are known to have less than ideal glycemic control on average, not meeting the target HbA1c value of <7.5% set by the American Diabetes Association (Silverstein et al., 2005), and this sample was no different. At 12 months after graduation, 59% of those with diabetes were living independently of parents, which is similar to the up to 56% of emerging adults in the general population who do so (Arnett, 2003; Goldscheider, 1997). However, although the participation rate was relatively high, the sample was self-selected from three settings in the Midwest and may not represent the national population of emerging adults with type 1 diabetes. In particular, these participants had relatively few depressive symptoms, possibly because those with serious mental health problems were excluded from the study.

Important statistical limitations include, first, the inflated Type I error rate (i.e., the possibility that some relationships judged to be significant were actually not significant) inherent in multiple non-independent tests such as were produced for each predictor variable included in the GLMM. Second, because the predictor variables were correlated, the individual regression weights and thus the contribution of each variable to the outcome were influenced by the set of predictors included in the model. A variable's lack of independent association with the outcome does not eliminate the possibility of an indirect or other type of relationship.

Further research is needed on DQOL of emerging adults with type 1 diabetes. To facilitate DQOL, an in-depth examination of the influence of independent living on quality of life is needed; living independently of parents may be too superficial an index of these youths' relationship with parents. Family co-management of diabetes for emerging adults with diabetes needs to be further explored for emerging adults who live independently of parents. Interventions to improve quality of life and diabetes management simultaneously need to be tested. If the relationship between diabetes management and quality of life is supported, health care professionals could be urged to attend to the relationship of diabetes management and diabetes-related quality of life.

Acknowledgments

The project was supported by the National Institute of Nursing Research at the National Institutes of Health (grant #R01NR009810). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Nursing Research or the National Institutes of Health.

References

Arnett JJ. Conceptions of the transition to adulthood among emerging adults in American ethnic groups. New Directions for Child and Adolescent Development. 2003; 100:63–75.10.1002/cd.75 [PubMed: 12955983]

Arnett JJ. Emerging adulthood: What is it, and what is it good for? Child Development Perspectives. 2007; 1:68–73.10.1111/j.1750-8606.2007.00016.x

Aseltine RH, Gore S. Mental health and social adaptation following the transition from high school. Journal of Research on Adolescence. 1993; 3:247–270.10.1207/s15327795jra0303_3

Barnard KD, Lloyd CE, Skinner TC. Systematic literature review: Quality of life associated with insulin pump use in Type 1 diabetes. Diabetic Medicine. 2007; 24:607–617.10.1111/j.1464-5491.2007.02120.x [PubMed: 17367304]

Beck, AT.; Steer, RA.; Brown, GK. BDI-II: Beck Depression Inventory Manual. 2nd. San Antonio, TX: Harcourt Assessment, Inc.; 1996.

Belsley, DA.; Kuh, E.; Welsch, RE. Regression diagnostics. New York, NY: John Wiley & Sons; 1980.

Bryden KS, Peveler RC, Stein A, Neil A, Mayou RA, Dunger DB. Clinical and psychological course of diabetes from adolescence to young adulthood: A longitudinal cohort study. Diabetes Care. 2001; 24:1536–1540.10.1016/j.dr.2007.08.003 [PubMed: 11522695]

Cole DA, Martin NC. The longitudinal structure of the Children's Depression Inventory: Testing a latent trait-state model. Psychological Assessment. 2005; 17:144–155.10.1037/1040-3590.17.2.144 [PubMed: 16029102]

College of American Pathologists. College of American Pathologists Survey Data. 2012. Retrieved from http://www.ngsp.org/CAPdata.asp

Côté J, Bynner JM. Changes in the transition to adulthood in the UK and Canada: The role of structure and agency in emerging adulthood. Journal of Youth Studies. 2008; 11:251–268.10.1080/13676260801946464

Delaney C. Rites of passage in adolescence. Adolescence. 1995; 30:891–897. [PubMed: 8588524]

Diabetes Control and Complications Trial Research Group. Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial. Journal of Pediatrics. 1994; 125:177–188.10.1016/S0022-3476(94)70190-3 [PubMed: 8040759]

Faulkner MS. Quality of life for adolescents with type 1 diabetes: Parental and youth perspectives. Pediatric Nursing. 2003; 29:362–368. [PubMed: 14651307]

Faulkner MS, Chang LI. Family influence on self-care, quality of life, and metabolic control in school-age children and adolescents with Type 1 diabetes. Journal of Pediatric Nursing. 2007; 22:59–68.10.1016/j.pedn.2006.02.008 [PubMed: 17234498]

Ferrans CE, Zerwic JJ, Wilbur JE, Larson JL. Conceptual Model of Health-Related Quality of Life. Journal of Nursing Scholarship. 2005; 37:336–342.10.1111/j.1547-5069.2005.00058.x [PubMed: 16396406]

Furstenberg, FF., Jr; Rumbaut, RC.; Settersten, RA, Jr. On the frontier of adulthood: Emerging themes and new directions. In: Settersten, RA.; Furstenberg, FF.; Rumbaut, RG., editors. On the frontier of adulthood: Theory, research, and public policy. Chicago, IL: The University of Chicago Press; 2005. p. 3-25.

Gillison F, Skevington S, Standage M. Exploring response shift in the quality of life of healthy adolescents over 1 year. Quality of Life Research. 2008; 17:997–1008.10.1007/s11136-008-9373-y [PubMed: 18633730]

Goldscheider F. Recent changes in U.S. young adult living arrangements in comparative perspective. Journal of Family Issues. 1997; 18:708–724.10.1177/019251397018006008

Graue M, Wentzel-Larsen T, Hanestad BR, Batsvik B, Sovik O. Measuring self-reported, health-related, quality of life in adolescents with type 1 diabetes using both generic and disease-specific instruments. Acta Paediatrica. 2003; 92:1190–1196.10.1080/08035250310005657 [PubMed: 14632337]

Graue M, Wentzel-Larsen T, Hanestad BR, Sovik O. Health-related quality of life and metabolic control in adolescents with diabetes: The role of parental care, control, and involvement. Journal of Pediatric Nursing. 2005; 20:373–382.10.1016/j.pedn.2005.08.005 [PubMed: 16182097]

Hanberger L, Ludvigsson J, Nordfeldt S. Health-related quality of life in intensively treated young patients with type 1 diabetes. Pediatric Diabetes. 2009; 10:374–381.10.1111/j.1399-5448.2008.00496.x [PubMed: 19207230]

Hanna KM. A framework for the youth with type 1 diabetes during the emerging adulthood transition. Nursing Outlook. 2012; 60:401–410.10.1016/j.outlook.2011.10.005 [PubMed: 22226223]

Hanna KM, Decker CL. A concept analysis: Assuming responsibility for self-care among adolescents with type 1 diabetes. Journal of Specialists in Pediatric Nursing. 2010; 15:99–110.10.1111/j.1744-6155.2009.00218.x

Hanna KM, Guthrie D. Adolescents' perceived benefits and barriers related to diabetes self-management--Part 1. Issues in Comprehensive Pediatric Nursing. 2000; 23:165–174.10.1080/01460860050174710 [PubMed: 11310236]

Hanna KM, Guthrie D. Adolescents' behavioral autonomy related to diabetes management and adolescent activities/rules. Diabetes Educator. 2003; 29:283–291. doi: org/10.1177/014572170302900219. [PubMed: 12728755]

Hanna KM, Weaver MT, Stump TE, Dimeglio LA, Miller AR, Crowder S, Fortenberry JD. Initial findings: Primary diabetes care responsibility among emerging adults with type 1 diabetes post high school and move out of parental home. Child: Care Health and Development. 2013; 39:61–68.10.1111/j.1365-2214.2011.01320.x

Hanna KM, Weaver ME, Stump TE, Fortenberry JD, DiMeglio LA. Worry about hypoglycemia among emerging adults with diabetes. Diabetes Educator. 2014; 40:533–542.10.1177/0145721714528997 [PubMed: 24676275]

Hanna KM, Weaver MT, Stump TE, Slaven JE, Fortenberry JD, DiMeglio LA. Readiness for living independently among emerging adults with type 1 diabetes. The Diabetes Educator. 2013; 39:92–99.10.1177/0145721712465341 [PubMed: 23150530]

Harris MA, Wysocki T, Sadler M, Wilkinson K, Harvey LM, Buckloh LM, White NH. Validation of a structured interview for the assessment of diabetes self-management. Diabetes Care. 2000; 23:1301–1304.10.2337/diacare.239.1301 [PubMed: 10977022]

Hassan K, Loar R, Anderson BJ, Heptulla RA. The role of socioeconomic status, depression, quality of life, and glycemic control in type 1 diabetes mellitus. Journal of Pediatrics. 2006; 149:526–531.10.1016/j.jpeds.2006.05.039 [PubMed: 17011326]

Helgeson VS, Escobar O, Siminerio L, Becker D. Relation of stressful life events to metabolic control among adolescents with diabetes: 5-year longitudinal study. Health Psychology. 2010; 29:153–159.10.1037/a0018163 [PubMed: 20230088]

Hoey H, Aanstoot HJ, Chiarelli F, Daneman D, Danne T, Dorchy H, Aman J. Good metabolic control is associated with better quality of life in 2,101 adolescents with type 1 diabetes. Diabetes Care. 2001; 24:1923–1928.10.2337/diacare.24.11.1923 [PubMed: 11679458]

Huang GH, Palta M, Allen C, LeCaire T, D'Alessio D. Self-rated health among young people with type 1 diabetes in relation to risk factors in a longitudinal study. American Journal of Epidemiology. 2004; 159:364–372.10.1093/aje/kwh055 [PubMed: 14769640]

Ingerski LM, Laffel L, Drotar D, Repaske D, Hood KK. Correlates of glycemic control and quality of life outcomes in adolescents with type 1 diabetes. Pediatric Diabetes. 2010; 11:563–571.10.1111/j.1399-5448.2010.00645.x [PubMed: 20149122]

Ingersoll GM, Marrero DG. A modified quality-of-life measure for youths: Psychometric properties. Diabetes Educator. 1991; 17:114–118.10.1177/014572179101700219 [PubMed: 1995281]

Insabella G, Grey M, Knafl G, Tamborlane W. The transition to young adulthood in youth with Type 1 diabetes on intensive treatment. Pediatric Diabetes. 2007; 8:228–234.10.1111/j.1399-5448.2007.00266.x [PubMed: 17659065]

Jacobson AM. The psychological care of patients with insulin-dependent diabetes mellitus. New England Journal of Medicine. 1996; 334:1249–1253.10.1056/NEJM199605093341907 [PubMed: 8606721]

Kutner, MH.; Nachtsheim, CJ.; Neter, J. Applied linear regression models. 4th. New York, NY: McGraw-Hill Irwin; 2004.

Lawrence JM, Yi-Frazier JP, Black MH, Anderson A, Hood K, Imperatore G. Group, S. f. D. i. Y. S. Demographic and clinical correlates of diabetes-related quality of life among youth with type 1 diabetes. Journal of Pediatrics. 2012; 161:201–207.e202.10.1016/j.jpeds.2012.01.016 [PubMed: 22361221]

Meleis, AI., editor. Transitions theory: Middle range and situation-specific theories in nursing research and practice. New York, NY: Springer Publishing Company; 2010.

Nansel TR, Weisberg-Benchell J, Wysocki T, Laffel L, Anderson B. Steering Committee of the Family Management of Diabetes, S. Quality of life in children with Type 1 diabetes: A comparison of general and diabetes-specific measures and support for a unitary diabetes quality-of-life construct. Diabetic Medicine. 2008; 25:1316–1323.10.1111/j.1464-5491.2008.02574.x [PubMed: 19046222]

Pereira MG, Berg-Cross L, Almeida P, Machado JC. Impact of family environment and support on adherence, metabolic control, and quality of life in adolescents with diabetes. International Journal of Behavioral Medicine. 2008; 15:187–193.10.1080/10705500802222436 [PubMed: 18696312]

Peters A, Laffel L, American Diabetes Association Transitions Working, G. Diabetes care for emerging adults: Recommendations for transition from pediatric to adult diabetes care systems: A position statement of the American Diabetes Association. Diabetes Care. 2011; 34:2477–2485.10.2337/dc11-1723 [PubMed: 22025785]

Schilling LS, Knafl KA, Grey M. Changing patterns of self-management in youth with type I diabetes. Journal of Pediatric Nursing. 2006; 21:412–424.10.1016/j.pedn.2006.01.034 [PubMed: 17101399]

Schneider S, Iannotti RJ, Nansel TR, Haynie DL, Simons-Morton B, Sobel DO, Plotnick LP. Identification of distinct self-management styles of adolescents with Type 1 diabetes. Diabetes Care. 2007; 30:1107–1112.10.2337/dc06-2197 [PubMed: 17322481]

Silverstein J, Klingensmith G, Copeland K, Plotnick L, Kaufman F, Laffel L, Clark N. Care of children and adolescents with type 1 diabetes: A statement of the American Diabetes Association. Diabetes Care. 2005; 28:186–212.10.2337/diacare.28.1.186 [PubMed: 15616254]

Steinberg, L. Adolescence. 8th. New York, NY: McGraw-Hill; 2008.

Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life A conceptual model of patient outcomes. The Journal of the American Medical Association. 1995; 273:59–65.10.1001/jama.273.1.59

Wolpert, HA.; Anderson, BJ.; Weisberg-Benchell, J. Transitions in care: Meeting the challenges of type 1 diabetes in young adults. Alexandria, VA: American Diabetes Association; 2009.

Table 1

Description of Variables in Emerging Adults with Diabetes

		At High School Graduation (*n* = 184 unless noted otherwise)					One Year After Graduation (*n* = 161 unless noted otherwise)				
		M	***SD***	**Range**	***n***	**%**	***M***	***SD***	**Range**	***n***	**%**
Outcome Variables	DQOL-Impact	47.1	10.5	27-88			44.7	10.5	28-82		
	DQOL-Worry	21.6	7.1	11-47			21.9	7.5	11-46		
	DQOL-Satisfaction	66.5	11.4	18-85			64.4	11.8	26-85		
	DQOL-Health Status	2.9	0.8	1-4			2.8	0.8	1-4		
							(*n* = 160)				
Predictor	Bias-adjusted HbA1c (%)	8.9	1.7	6.2-14.2			9.1	2.1	6.0-15.0		
Variables		(*n* = 161)					(*n* = 84)				
	Diabetes management	51.4	11.7	15-82			51.1	12.9	23-80		
	Primary diabetes care	43.1	16.6	17-100			56.5	23.1	17-100		
	responsibility						(*n* = 158)				
	Living independently of parents				7	9.0				95	59.4
					(*n* = 78)					(*n* = 160)	
Covariates	Years with diabetes	8.5	4.0	1-18							
	Insulin administration method (CSII)				89	48.4				90	55.9
	Gender (female)				104	56.5					
	Depressive symptoms	7.3	8.1	0-49							
		(*n* = 183)									

Note. *M*=Mean, *SD*=standard deviation, DQOL= Diabetes-related Quality of Life (Modified Quality-of-Life Measure for Youths, Ingersoll & Marrero, 1991), HbA1c= hemoglobin A1c, Diabetes management=Emerging Adult Diabetes Management Self-Report adapted from Diabetes Self-Management Profile (Harris et al., 2000), Primary diabetes care responsibility= revised version of Independent Functioning and Decision-making in Daily and Non-Daily Diabetes Management Checklist (Hanna & Guthrie, 2003), CSII= continuous subcutaneous insulin infusion, Depressive symptoms= BDI=Beck Depression Inventory-Second Edition (Beck, Steer, & Brown, 1996).

Table 2
Association of DQOL Subscales with Predictors and Covariates in Final GLMM Models

Outcome	Predictor or Covariate	Parameter Estimate	*F (df)*	*p*
DQOL-Impact	HbA1c (bias-adjusted)	0.66	2.02 (1, 19)	0.17
	Diabetes management	-0.14	5.12 (1, 19)	0.04
	Primary diabetes care responsibility	0.01	0.02 (1, 19)	0.88
	Time (HS graduation vs. 1 year)	-2.82	4.17 (1, 19)	0.06
	Living independently of parents	0.23	0.02 (1, 19)	0.89
	Insulin administration method (CSII)	1.10	0.48 (1, 4)	0.53
	Time with diabetes (years)	-0.28	1.57 (1, 108)	0.21
	Gender (female)	-1.26	0.47 (1, 108)	0.50
	Depressive symptoms (BDI ≥14)	16.86	34.03 (1, 108)	<0.01
DQOL-Worry	HbA1c (bias-adjusted)	0.10	0.10 (1, 19)	0.75
	Diabetes management	-0.10	5.08 (1, 19)	0.04
	Primary diabetes care responsibility	-0.00	0.01 (1, 19)	0.93
	Time (HS graduation vs 1 year)	-0.56	0.31 (1, 19)	0.58
	Living independently of parents	-0.52	0.19 (1, 19)	0.67
	Insulin administration method (CSII)	1.65	2.18 (1, 4)	0.21
	Time with diabetes (years)	-0.21	1.88 (1, 108)	0.17
	Gender (female)	1.21	0.89 (1, 108)	0.35
	Depressive symptoms (BDI ≥14)	11.54	33.06 (1, 108)	<0.01
DQOL-Satisfaction	HbA1c (bias-adjusted)	-0.85	3.22 (1, 19)	0.09
	Diabetes management	0.16	6.63 (1, 19)	0.02
	Primary diabetes care responsibility	-0.05	1.42 (1, 19)	0.25
	Time (HS graduation vs 1 year)	1.95	2.66 (1, 19)	0.12
	Living independently of parents	-3.37	4.83 (1, 19)	0.04
	Insulin administration method (CSII)	-1.28	0.71 (1, 4)	0.45
	Time with diabetes (years)	0.31	1.64 (1, 108)	0.20
	Gender (female)	0.81	0.16 (1, 108)	0.69
	Depressive symptoms (BDI ≥14)	-17.15	28.70 (1, 108)	<0.01
DQOL-Health Status	HbA1c (bias-adjusted)	-0.03	0.46 (1, 19)	0.52
	Diabetes management	0.02	8.52 (1, 19)	0.01
	Primary diabetes care responsibility	-0.00	0.12 (1, 19)	0.75
	Time (HS graduation vs 1 year)	0.01	0.00 (1, 19)	0.96
	Living independently of parents	0.08	0.23 (1, 19)	0.59
	Insulin administration method (CSII)	-0.30	4.88 (1, 4)	0.09
	Time with diabetes (years)	0.02	1.30 (1, 107)	0.22
	Gender (female)	-0.36	6.08 (1, 107)	0.02
	Depressive symptoms (BDI ≥14)	-0.42	3.37 (1, 107)	0.08

Note. GLMM= general linear mixed models, DQOL= diabetes-related quality of life (Modified Quality-of-Life Measure for Youths, Ingersoll & Marrero, 1991), Diabetes management=Emerging Adult Diabetes Management Self-Report adapted from interview format of the Diabetes Self-Management Profile (Harris et al., 2000), Primary diabetes care responsibility= revised version of Independent Functioning and Decision-making

in Daily and Non-Daily Diabetes Management Checklist (Hanna & Guthrie, 2003), HbA1c= hemoglobin A1c, CSII=continuous subcutaneous insulin infusion, BDI=Beck Depression Inventory-Second Edition (Beck, Steer, & Brown, 1996).