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Associations Between Major Life Events and Adherence, Glycemic Control, and Psychosocial Characteristics in Teens with Type 1 Diabetes

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Abstract

Aims—This cross-sectional study assessed the type of major life events occurring in a contemporary sample of teens with type 1 diabetes and the association between event frequency and demographic, diabetes management, and psychosocial characteristics.

Methods—Parents of 178 teens completed the Life Events Checklist to report major events teens had experienced in the last year: 42% experienced 0–1 event (n=75), 32% experienced 2–3 events (n=57), and 26% experienced 4+ events (n=46). Teens and parents completed validated measures of treatment adherence, diabetes-specific self-efficacy, quality of life, and diabetes-specific family conflict. Parent-youth interview and chart review provided demographics and diabetes management data.

Results—Mean number of events/teen was 2.6 ± 2.7 (range=0–15). The most common events were “Hospitalization of a family member” (24%), “Getting a bad report card” (20%), “Serious arguments between parents” (19%), and “Serious illness/injury in a family member” (19%). Compared with teens experiencing 0–1 event, teens experiencing 4+ events were less likely to have married parents ($p=0.01$) and a parent with a college degree ($p=0.006$). Teens with 4+ events had significantly poorer adherence ($p=0.002$ teen, $p=0.02$ parent), lower self-efficacy ($p=0.03$ teen, $p<0.0001$ parent), poorer quality of life ($p<0.0001$ teen, $p<0.0001$ parent), and more conflict ($p=0.006$ teen, $p=0.02$ parent) than teens with fewer events. In a multivariate model ($R^2=0.21$, $p<0.0001$) controlling for demographic and diabetes management characteristics, fewer events was associated with lower A1c ($p=0.0009$).

Conclusions—Occurrence of more major life events was associated with poorer diabetes care and A1c and more negative psychosocial qualities in teens with type 1 diabetes.

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CONFLICTS OF INTEREST

L.M.L. reports participation as a consultant for AstraZeneca, Boehringer Ingelheim Pharmaceuticals, Inc., Dexcom, Inc., Eli Lilly and Company, Johnson & Johnson, Novo Nordisk Inc., Roche Diagnostics, and Sanofi.

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Keywords

Type 1 diabetes mellitus; Adolescent; Life change events; Patient adherence; Hemoglobin A1c

BACKGROUND

Adolescence is marked by a number of normative challenges, such as physical growth and pubertal development with associated hormonal changes, transitions to new schools, desire for greater independence from parents, fitting in with peers, and navigating romantic relationships (1–4). Teens with type 1 diabetes experience these developmental challenges along with the added burden of diabetes self-care. The management of type 1 diabetes in youth requires time-intensive efforts, disrupts typical daily activities, and adds more responsibilities upon teens and their family members related to timely diabetes care (5). Adolescence has been recognized as a particularly difficult period to engage in diabetes management as many teens demonstrate declining adherence and deteriorating glycemic control. In addition to the natural, physiological insulin resistance during puberty (6), typical adolescent emotional lability may affect motivation to perform self-care, particularly when diabetes management is viewed as interfering with peer acceptance or independence from parents (7, 8). At this developmental stage of increased cognitive demands, chronic illnesses, such as type 1 diabetes, can cause significant stress, as well as be impacted by other major life stressors (9).

Discrete events may act as stressors that could have a negative impact on the teen. For example, teens may be particularly affected by parental divorce, a blended family after parent re-marriage, changing schools, or moving to a new home (10). Additionally, daily stressors such as issues in friendships or romantic relationships, academic stressors, and body-image issues such as weight or acne (10) may further compound the effect of major, stressful life events. Prior research has shown that the occurrence of more negative life events in teens is associated with higher levels of depression and anxiety, lower self-esteem, and behavioral problems such as substance use and self-harm (11–14).

For teens with type 1 diabetes, major life events may not only disrupt daily life, but can also have a negative impact on their treatment regimen, self-confidence in their ability to perform diabetes tasks, personal relationships and support for treatment, quality of life, and even blood glucose levels by affecting physiologic stress levels. Past studies have found that general stress is indirectly related to poorer glycemic control through the reduction of self-care and adherence behaviors (1, 15). Additionally, teens with type 1 diabetes have been found to be at higher risk of depression, anxiety, and disordered eating than their peers without diabetes, further negatively affecting their self-care behaviors and glycemic control (16–19). When negative psychological and social effects of stressful life events are coupled with declining adherence to diabetes self-care, teens with type 1 diabetes appear to be at significantly greater risk of worsening glycemic control.

As previous research has shown, the occurrence of major life events or stressors in a teen's life may interfere with attendance to self-care activities (1, 15, 20). Screening for major life events may assist healthcare providers in identifying potential causes of sub-optimal

adherence, thus allowing providers to address the specific challenges faced by the teen and family and provide appropriate support and intervention. Screening for commonly occurring life events also affords healthcare providers with the opportunity to identify teens at-risk for negative health outcomes and in need of early intervention to prevent deteriorations in adherence and health outcomes. The current study assessed the frequency and type of parent-reported major life events occurring in a contemporary sample of teens with type 1 diabetes through the use of an abbreviated screening tool. Additionally, we sought to evaluate the demographics, diabetes management characteristics, and parent- and teen-reported psychosocial characteristics associated with the occurrence of major life events. We hypothesized that the report of greater number of life events would be associated with poorer glycemic control, less treatment adherence, and more negative psychosocial qualities.

METHODS

Participants

Teens with type 1 diabetes and a parent were recruited from a large pediatric diabetes center to participate in the study. A total of 416 eligible teens were approached regarding their interest in a longitudinal RCT and 184 (44%) consented; the primary reason for declining to participate was limited interest in participating in the longitudinal RCT. One parent did not complete the Life Events Checklist (LEC); this teen/parent dyad was excluded from analyses. Five sibling pairs participated in the study; for each of these families, data for the sibling with shorter diabetes duration were excluded from analyses. Thus, a total of 178 teens and their parents provided data for analysis from a single study visit. Teen participants were ages 13–17 years, with duration of type 1 diabetes ≥ 6 months. Additional eligibility criteria included insulin dose ≥ 0.5 U/kg/day and an A1c of 48–97 mmol/mol (6.5–11.0%). The institutional review board approved the study protocol and written informed consent (parent) and assent (teen) were obtained for 184 teens prior to completion of any study procedures. Teens received \$30 and parents received \$10 for their time and effort for study visit/survey completion.

Measures

Demographic and Diabetes Management Characteristics—Chart review and parent-youth interview provided data on sex, race, parent marital status, parent education level, diabetes duration, insulin regimen, and frequency of blood glucose monitoring. Glycemic control, measured as A1c, was obtained and measured uniformly using Roche Cobas Integra (Ref. range: 4–6%; Roche Diagnostics, Indianapolis, IN).

Psychosocial Characteristics—Teens and parents completed the following collection of previously validated measures. The measures were completed on tablet computers using REDCap, a secure, web-based application designed to support data capture for research studies (21). Total scores for all measures were transformed to a 0 to 100 scale for ease of interpretation and comparison.

Treatment Adherence: The Diabetes Management Questionnaire (DMQ) (22) was used to measure treatment adherence in the previous month, as reported by both teen and parent.

The scale contains 20 items on a 5-point Likert response scale (“Almost Never” to “Almost Always”) to assess perceptions of how often the teen and parent adhered to treatment recommendations for exercise, mealtimes, treatment of low and high blood glucose levels, blood glucose monitoring, and insulin administration. Higher scores indicate greater adherence to prescribed treatment regimens.

Diabetes-Specific Self-Efficacy: The Diabetes Management Self-Efficacy Survey (DMSE) (23) was used to measure teen self-efficacy through teen report and parent proxy-report. Teens and parents rated their confidence in the teen’s ability to perform 16 listed self-care tasks on a 5-point Likert response scale (“Disagree a Lot” to “Agree a Lot”). Higher scores indicate more confidence in the teen’s ability to perform diabetes self-care tasks.

General Quality of Life: The Pediatric Quality of Life Inventory 4.0 - Generic Core Scales (PedsQL) (24) was used to measure overall quality of life based on report of problems with physical functioning and psychosocial (social, emotional, and school) functioning by both teen report and parent proxy-report. The measure consists of 23 items on a 5-point Likert scale (“Never a Problem” to “Almost Always a Problem”), with higher scores indicating better quality of life.

Diabetes-Specific Family Conflict: The Diabetes Family Conflict Scale (DFCS) (25) was used to measure the frequency of conflict within the family surrounding diabetes care by both teen and parent report. The measure consists of 19 items rated on a 3-point Likert scale (“Almost Never” to “Almost Always”), with higher scores indicating more conflict.

Major Life Events: An updated version of the Life Events Checklist (LEC) (26) was used to measure major life events experienced by teens in the last 12 months by parent proxy-report. Parents indicated (“Yes” or “No”) whether any of 25 listed life events had occurred; there was space to write in up to four additional unlisted events. Additional write-in responses were reviewed by two members of the study team (PVC, LKV) and recoded as one of the 25 listed events when applicable; the remaining write-in responses were retained as “other” events. Total scores were calculated by summing the number of endorsed events (including “other” events). The 25 listed items included both objective (e.g., “Death of a family member”) and subjective (e.g., “Getting a bad report card”) events.

Statistical Analyses

We divided participants into three groups based on the total number of life events endorsed: 0–1, 2–3, and 4 or more life events, as the data were not normally distributed and thus better suited to categories. We compared demographic, diabetes management, and psychosocial characteristics among the three life events groups using ANOVA and Chi-square analyses. We used a multivariate regression model to assess the relationship between major life events and A1c while controlling for several demographic and diabetes management variables. Significance was defined as a p-value <0.05. Statistical analyses were performed using SAS (version 9.4; SAS Institute, Inc., Cary, NC).

RESULTS

Demographic and diabetes management characteristics for the entire sample appear in Table 1; psychosocial characteristics appear in Table 2. The sample was composed of 178 teens, 47% female and 88% non-Hispanic White. Additionally, 82% of teens came from homes with married parents and 72% had at least one parent with a college degree or higher. The mean age of the sample was 14.9 ± 1.3 years and mean duration of type 1 diabetes was 7.3 ± 3.7 years. Mean blood glucose monitoring frequency was 5.3 ± 1.9 times per day and 75% used an insulin pump. Overall glycemic control was suboptimal, with a mean A1c of 69 ± 11 mmol/mol ($8.5 \pm 1.0\%$), and only 16% of the sample achieved target A1c of <58 mmol/mol ($<7.5\%$).

Major life events were tallied based on parent endorsement of each of the 25 life events listed plus other write-in responses on the Life Events Checklist to determine most commonly occurring life events in the sample. The most commonly endorsed life events appear in Table 3. According to parents, the most frequently endorsed event was “Hospitalization of a family member” (24%). The other most commonly reported events were: “Getting a bad report card” (20%), “Serious arguments between his or her parents” (19%), “Serious illness/injury in a family member” (19%), “Going to a new school” (17%), “Serious arguments with his or her family members” (16%), “Death of a family member” (16%), “Financial problems in the family” (16%), and “Failing a grade” (14%). The number of endorsed life events in the last year ranged from 0 to 15 events, with a mean of 2.6 events and median of 2 life events (Fig. 1). The most frequently reported number of life events was 0 life events ($n=38$).

Next, we stratified the sample into three groups according to number of life events reported in order to better facilitate comparison. The percentage of participants in each of the three life events groups was: 0–1 events: 42% ($n=75$), 2–3 events: 32% ($n=57$), and 4+ events: 26% ($n=46$). We then compared the groups across three distinct factors: demographic characteristics, diabetes management characteristics, and psychosocial characteristics. Demographic and diabetes management characteristics for the three life events groups appear in Table 4. Regarding demographic characteristics, there were no differences among groups based on age, diabetes duration, sex, or race/ethnicity. However, there was a significant difference among groups based on parent marital status and parent education: more life events were associated with unmarried parents (0–1 vs. 4+ events, $p=0.006$) and parents without a college degree (0–1 vs. 4+ events, $p=0.004$; 2–3 vs. 4+ events, $p=0.02$). In terms of diabetes management characteristics, there were no differences among groups with respect to pump use and blood glucose monitoring frequency. However, A1c was significantly lower in the group endorsing fewer life events: the 0–1 life events group had a mean A1c of 66 ± 9 mmol/mol ($8.2 \pm 0.8\%$) compared to 76 ± 12 mmol/mol ($9.1 \pm 1.1\%$) in the group endorsing 4 or more life events, with the group endorsing 2–3 life events displaying an intermediate A1c of 69 ± 11 mmol/mol ($8.5 \pm 1.0\%$) (0–1 vs. 4+ events, $p<0.0001$; 2–3 vs. 4+ events, $p=0.02$). In a multivariate model (model: $R^2=0.21$, $p<0.0001$) controlling for age, diabetes duration, insulin regimen, blood glucose monitoring frequency, parent education, and parent marital status, fewer life events remained significantly associated with lower A1c (0–1 vs. 2–3 events, $p=0.06$; 0–1 vs. 4+ events, $p=0.0002$; 2–3 vs. 4+ events, $p=0.04$); higher

parent education ($p=0.03$) and more frequent blood glucose monitoring ($p=0.007$) were also associated with lower A1c.

Finally, the three life events groups were compared on multiple psychosocial domains measured by teen and parent or parent-proxy reports: treatment adherence, diabetes management self-efficacy, quality of life, and diabetes-specific family conflict (Fig. 2a and Fig. 2b). There were similar trends for both teen- and parent-reported scores. Teens whose parents endorsed 4+ life events reported significantly lower treatment adherence ($p=0.001$), self-efficacy ($p=0.02$), and quality of life ($p<0.0001$), as well as higher family conflict ($p=0.01$) compared with teens whose parents endorsed 0–1 life event (Fig. 2a). In addition, teens whose parents endorsed 2–3 life events reported significantly lower quality of life ($p=0.03$) and higher family conflict ($p=0.03$) than teens whose parents endorsed 0–1 life event. Similarly, parents endorsing 4+ life events reported significantly lower treatment adherence ($p=0.02$), teen self-efficacy ($p<0.0001$), and teen quality of life ($p<0.0001$), as well as higher family conflict ($p=0.02$) compared with parents who endorsed 0–1 life event (Fig. 2b). Parents who endorsed 4+ life events also reported significantly lower self-efficacy in their teen than parents who endorsed 2–3 life events ($p=0.04$). In addition, parents who endorsed 2–3 life events reported significantly lower teen self-efficacy ($p=0.02$) and teen quality of life ($p=0.001$) than parents who endorsed 0–1 life event. Of note, statistical analyses using life events as a continuous variable showed parallel results in that greater life events was associated with significantly poorer glycemic control and adherence, as well as more negative psychosocial outcomes.

DISCUSSION

The current study highlights an opportunity for clinical care teams to improve health outcomes in teens with type 1 diabetes through regular screenings for stressful life events. These screenings allow providers to identify teens at risk for adverse biomedical outcomes and psychosocial qualities and provide appropriate support and intervention. Our results showed that report of greater numbers of stressful life events was significantly associated with parent-specific demographics, teen diabetes management characteristics, and both teen- and parent-reported psychosocial factors. These data contribute to the existing literature on the association between stressful life events and diabetes care.

Demographic characteristics associated with endorsement of a greater number of life events included unmarried parental status and lower parent education level. Past research has suggested that prestige-related factors indicative of higher socioeconomic status, such as higher parent education, was related to fewer negative life events influenced or caused by teen behaviors, such as poor grades on an exam or failing to find employment (27). Teens experiencing more life events also experienced deleterious effects on diabetes management, including significantly lower treatment adherence and poorer glycemic control compared to teens with fewer major life events. It is possible that more major life events affect the teens' willingness and/or capability to engage in self-care, thus worsening A1c. Finally, more life events were associated with lower diabetes self-efficacy, lower perceived overall quality of life, and more diabetes-specific family conflict. It is possible that when teens need to cope with major life events, their confidence in their ability to manage their diabetes and their

perceived quality of life are compromised, and the frequency of diabetes-specific family conflict in the home is higher. The substantial difference among the three groups of life events on demographic, diabetes-management, and psychosocial characteristics suggests that having multiple life events may have a synergistic effect upon these diabetes-related outcomes.

The direction of the relationship between life events and the listed demographic, diabetes-related, and psychosocial characteristics is unclear. For example, “Failing a grade” could cause issues with overall self-confidence that lead to lower diabetes self-efficacy and treatment adherence and increase conflict, or “Failing a grade” could be the result of difficulty concentrating or learning with high blood glucose levels caused by low treatment adherence. On the other hand, “Death of a family member” may be the cause of lower perceived quality of life but is unlikely to be influenced by any of the demographic, diabetes management, or psychosocial characteristics. Future research on the impact of such uncontrollable versus controllable life events on diabetes-related outcomes would be beneficial to analyze.

Endorsed events also raise questions regarding objectivity and perceived severity. As only parents completed the Life Events Checklist, descriptive terms such as “bad” grades or “serious” arguments were indicative of parent-perceptions only. This raises the question of interpretation, as parents may differ from their teens as to which grades they consider “bad” or when arguments and injuries become “serious” or problematic. Similarly, the perceived impact or severity of these items on teens would be beneficial to assess, as teens and parents may handle situations such as “Hospitalization of a family member” or “Family financial problems” differently. Teens may also have varying degrees of exposure to such situations (e.g., distant relatives or parents shouldering financial strains on the family) that may affect the degree to which these events impact teens’ lives. Notably, the item “Going to a new school” may insinuate a disruptive or negative event when, in fact, transition to a new school is an age-appropriate transition for teens entering high school.

Some limitations for the current study should be noted. The sample was primarily non-Hispanic White, potentially limiting generalizability. The methodology used was cross-sectional, thus causality cannot be determined. Additionally, data regarding the perceived impact of life events would have provided a more detailed perspective on the assessed relationships. Although there is always a potential for response bias with self-report measures, we anticipate that completion of teen and parent surveys on tablet computers would provide a greater sense of anonymity regarding one’s responses and therefore would help to decrease the potential for response bias due to social desirability. Finally, life events data were collected through parent report only; perspectives of the teen should be assessed in the future.

In the current study, major life events were associated with biomedical and psychosocial characteristics. By identifying teens experiencing major stressors, and teaching them psychological techniques to lessen the negative impact on their lives, we may be able to improve diabetes control and emotional well-being. The teens in our sample may differ from teens with type 1 diabetes in the general population with regard to specific demographic and

diabetes management characteristics. However, we expect that the patterns associated with more life events in our sample would be generalizable to the broader population of teens with type 1 diabetes; these patterns include poorer diabetes management and glycemic control, as well as more negative perceptions of diabetes-specific self-efficacy, general quality of life, and diabetes-specific family conflict.

Future directions include the development of an updated screening measure that includes stressful life events relevant to the current era (e.g., cyber bullying). Screenings should assess the perceived impact of the event on both teens and parents, taking care to differentiate between teen-influenced events (e.g., grades) and random events (e.g., illness or injury). The impact of various life events should also be assessed longitudinally to assess their long-term impact on glycemic control and psychosocial qualities.

These findings underscore the existing literature describing the effects of stressful life events on diabetes care, and highlight a potential tool for improving glycemic control and reducing negative psychosocial qualities in teens. Regular screening for major life events among teens, a group at risk for suboptimal diabetes control and more negative psychosocial qualities, may provide a means to easily identify those at high risk. As the screening would only assess the occurrence of major life events, such screenings for major life events do not require access to a trained mental health professional for administration, scoring, or follow-up in the same way as screenings for depression or anxiety. Similarly, screening for life events does not require purchase of a proprietary survey. Additionally, brief screenings for life events could be quickly completed in clinic and provide valuable information for providers to consider when discussing the teen's difficulties with diabetes care. Though providers can ask about life events in lieu of a traditional screener, a standardized measure applicable to a contemporary sample of teens provides a nonjudgmental, uniform list for parents or teens to complete, possibly with less embarrassment. Endorsed items can direct the healthcare team's follow-up queries and may offer further information on how diabetes care plays into the current status of the teen's life. Once teens and families in need of further assistance are identified by virtue of the presence of major, stressful life events, multidisciplinary diabetes team members can intervene with additional diabetes medical and psychosocial support. Such timely intervention may help to reduce the impact of these life stressors on teens and their parents by teaching them the necessary coping skills to manage these major life events without negatively affecting their mental health, relationships, or diabetes care.

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Figure 1. Distribution of life event frequencies

Frequencies ranged from 0–15 events, with the most commonly endorsed number of life events being 0 or 1 event. 42% of teens ($n=75$) experienced 0–1 life event (yellow bars), 32% of teens ($n=57$) experienced 2–3 life events (blue bars), and 26% of teens ($n=46$) experienced 4 or more life events (black bars).

Figure 2a. Associations between teen-reported psychosocial characteristics and life events
 Teens who experienced more life events reported significantly lower treatment adherence ($p=0.002$), self-efficacy ($p=0.03$), and quality of life ($p<0.0001$), as well as higher family conflict ($p=0.006$), compared with teens who experienced fewer life events. P values shown are for overall ANOVAs. Yellow bars=0–1 event. Blue bars=2–3 events. Black bars=4+ events.

Figure 2b. Associations between parent-reported psychosocial characteristics and life events
 Parents of teens who experienced more life events reported significantly lower treatment adherence ($p=0.02$), teen self-efficacy ($p<0.0001$), and teen quality of life ($p<0.0001$), as well as higher family conflict ($p=0.02$), compared with parents of teens who experienced fewer life events. P values shown are for overall ANOVAs. Yellow bars=0–1 event. Blue bars=2–3 events. Black bars=4+ events.

Table 1

Demographic and Diabetes Management Characteristics (N=178)

	M±SD or %
Age (years)	14.9±1.3
Duration of T1D (years)	7.3±3.7
Sex (% female)	47
Race/Ethnicity (% non-Hispanic white)	88
Regimen (% pump-treated)	75
Parent Marital Status (% married)	82
Parent Education (% college graduate)	72
BG Monitoring Frequency (times/day)	5.3±1.9
A1c (mmol/mol; %)	69±11 (8.5±1.0)

Table 2

Psychosocial Characteristics

	M±SD (Range)		Cronbach's alpha	
	Teen	Parent	Teen	Parent
Treatment Adherence	72±12 (41–98)	71±14 (36–98)	0.72	0.82
Diabetes-Specific Self-Efficacy	83±13 (43–100)	71±20 (5–100)	0.85	0.92
Youth Quality of Life	85±13 (24–100)	83±13 (42–100)	0.92	0.91
Diabetes-Specific Family Conflict	19±24 (0–100)	15±14 (0–95)	0.96	0.89

Table 3

Most Commonly Endorsed Life Events

MAJOR LIFE EVENT	%
Hospitalization of a family member	24
Getting a bad report card	20
Serious arguments between his/her parents	19
Serious illness/injury in family member	19
Going to a new school	17
Serious arguments with his/her family members	16
Death of a family member	16
Financial problems in the family	16
Failing a grade	14

Table 4

Demographic and Diabetes Management Characteristics According to Life Events Groups

	0–1 Life Events	2–3 Life Events	4+ Life Events
Age (years)	15.0±1.4	14.8±1.3	15.0±1.9
Duration of T1D (years)	7.5±3.8	7.3±3.6	7.0±3.8
Sex (% female)	51	46	43
Race/Ethnicity (% non-Hispanic White)	91	88	83
Parent Marital Status (% married) *	91	81	70
Parent Education (% college graduate) †	80	77	54
Regimen (% pump)	83	72	65
BGM Frequency (times/day)	5.5±1.8	5.3±2.0	4.8±1.9
A1c (mmol/mol; %) ‡	66±9 (8.2±0.8)	69±11 (8.5±1.0)	76±12 (9.1±1.1)

* 0–1 vs. 4+ events: p=.006

† 0–1 vs. 4+ events: p=.004; 2–3 vs. 4+ events: p=.02

‡ 0–1 vs. 4+ events: p<.0001; 2–3 vs. 4+ events: p=.02