

HHS Public Access

Author manuscript *J Adolesc Health.* Author manuscript; available in PMC 2018 February 01.

Published in final edited form as:

J Adolesc Health. 2017 February ; 60(2): 212–218. doi:10.1016/j.jadohealth.2016.09.004.

Clinical and psychosocial outcomes of a structured transition program among young adults with type 1 diabetes

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Abstract

Purpose—We identified and treated young adults with type 1 diabetes who had been lost to follow-up during their transfer from pediatric to adult care, comparing their clinical, psychosocial, and healthcare utilization outcomes to participants receiving continuous care throughout the transition to adult care.

Methods—Individuals in their last year of pediatric care ("Continuous Care" group, CC, n=51) and individuals lost to follow-up in the transfer to adult care ("Lapsed Care" Group, LC, n=24) were followed prospectively for 12 months. All participants were provided developmentally tailored diabetes education, case management, and clinical care through a structured transition program.

Results—At baseline, LC participants reported lapses in care of 11.6 months. Compared to CC participants, they had higher A1C (p=0.005), depressive symptoms (p=0.05), incidence of severe hypoglycemia (p=0.005), and emergency department visits (p=0.004). At 12-month follow-up, CC and LC participants did not differ on the number of diabetes care visits (p=0.23), severe hypoglycemia (no events), or emergency department visits (p=0.22). Both groups' A1C improved during the study period (CC p=0.03; LC p=0.02). LC participants' depressive symptoms remained

Conflict of Interest Statement: The authors do not disclose any conflicts of interest.

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elevated (p=0.10), and they reported a decline in life satisfaction (p=0.007). There was greater loss to follow-up in the LC group (p=0.04).

Conclusions—Our study suggests that, for young adults with a history of lapses in care, a structured transition program is effective in lowering A1C, reducing severe hypoglycemia and emergency department utilization, and improving uptake of routine diabetes care. Loss to follow-up and psychosocial concerns remain a significant challenge in this population.

Keywords

diabetes mellitus, type 1; transition to adult care; continuity of patient care

Transitioning from pediatric to adult healthcare can be a significant challenge for youth with chronic conditions. Due to developmental and health system characteristics, there is often a mismatch between the responsibilities that young adults are expected to assume with respect to managing their chronic illness, and those they are equipped to carry out successfully. (1) As a result, many young adults experience a loss to follow-up when they transfer from pediatric to adult care. (2) Among youth with type 1 diabetes, 34% have gaps in care of greater than 6 months during this transition (3), and clinic attendance typically decreases following the transition to adult care. (4) The strongest predictors of such lapses in care are the lack of a referral to a specific adult provider (including name and contact information), competing life priorities, and insurance problems (5). Conversely, young adults who report feeling mostly, or completely, prepared for transition have a lower likelihood of experiencing a gap in care of greater than 6 months. (3) In addition to poor clinic attendance, health and psychosocial well-being often decline during this life stage, with only 14% of young adults meeting recommended targets for glycemic control (6), fewer than 1/3 meeting diabetes selfcare recommendations (7), and many experiencing poor psychosocial well-being (8). These issues, coupled with poor clinical follow-up, significantly increase young adults' risk of developing diabetes-related complications.

Although the challenges surrounding transition have been well-documented, there are few reports describing the health status and psychosocial well-being of young adults who have experienced a gap in care during transition. In this study, we report on findings from a prospective, non-randomized trial which compared two cohorts of transition-age youth with type 1 diabetes: one group that had continual access to care prior to study enrollment, and another that had experienced a lapse in medical care prior to study enrollment, during their transfer from pediatric to adult healthcare. During the study, both groups had ongoing access to clinical care, case management, and diabetes education. In this paper we compare the demographic, clinical, psychosocial and healthcare utilization characteristics of both groups over the course of the 12-month study period.

Methods

Study design

The Helmsley T1D Transition "Let's Empower and Prepare" (LEAP) Program (Leona and Harry Helmsley Charitable Trust #2010PG-T1D011; PI: A. Peters) was a three-arm trial (continuous care group, lapsed care group, and control group) which evaluated the efficacy

of a structured transition program. This paper compares outcomes between the continuous care group (CC): young adults who received transition support throughout their last year of pediatric care, and the lapsed care group (LC): young adults who had experienced a disruption in care during the transition from pediatric to adult care. A comparison of outcomes between the CC group and a control group not reported on in this article, as well as a mixed-methods analysis of LC group characteristics, are reported elsewhere. (12, 13) The study procedures were approved by the University of Southern California Institutional Review Board. Informed consent was obtained from each participant by a study coordinator at the time of enrollment.

Recruitment and enrollment

CC participants were recruited at a major urban children's hospital and a large public hospital in Los Angeles County. LC participants were recruited from local community health centers, emergency departments, referrals of former patients by pediatric providers, and referrals of friends and acquaintances by enrolled participants (snowball sampling). Eligibility criteria for all participants included the following: (1) age 19–25 at time of study enrollment; (2) diagnosis of type 1 diabetes according to ADA criteria for at least 2 years; and (3) participant not pregnant at time of study enrollment or planning pregnancy within the next 12 months. Additional eligibility criteria for LC participants included either: (1) having no identified adult diabetes care provider and no routine diabetes care visits in the past 3 months; or (2) having been discharged from pediatric care without an identified adult diabetes care provider. Additional eligibility criteria for CC participants included the following: (1) participant was receiving routine diabetes care by a known provider at time of study enrollment; and (2) participant anticipated transferring from pediatric to adult care within the 12 months following study enrollment.

Data collection

The primary outcome, evaluated through review of medical records at each facility and supplemented by self-report, was the number of routine diabetes care visits (including both pediatric and adult care visits) at the study's participating clinics during the 12-month study period. Routine diabetes care visits were defined as clinic visits where an A1C measurement was taken (typically on a quarterly basis).

Secondary outcomes included glycemic control (A1C), episodes of severe hypoglycemia (defined as requiring assistance and/or change in mental status), emergency department visits, hospitalizations, and psychosocial outcomes. A1C values were measured at study visits at baseline, 6, and 12 months using the DCA 2000 analyzer (Bayer Inc., Tarrytown, NY, USA), supplemented by medical chart data from the study's participating clinics for participants who missed study visits. All other secondary endpoints were evaluated by self-report via a computerized survey during study visits at baseline and 12 months.

Psychosocial surveys administered at baseline and 12 months included the Diabetes Empowerment Scale-Short-Form (DES-SF), an 8-item measure of diabetes self-efficacy (14); the Diabetes Knowledge Test (DKT), a 14-item measure of general diabetes knowledge (15); the adapted Perceived Stress Scale (PSS), a 17-item measure evaluating one's

perception of life as stressful within the past month, adapted for increased comprehension by Hispanic adolescents (16, 17); the Patient Health Questionnaire-9 (PHQ-9), a 9-item measure of depressive symptoms (18); the Satisfaction with Life Scale (SWLS), a 5-item measure of global life satisfaction (19); and the Arizona Integrative Outcomes Scale (AIOS)-24 and AIOS-30, single-item visual analogue scales measuring an individual's overall physical, emotional, and spiritual well-being over the past 24 hours and 30 days, respectively (20).

Intervention

The LEAP intervention, modeled after the *Sweet* transition program (Milton, OLD, Australia) and informed by qualitative data from local pediatric care providers, adolescent and young adult patients with T1D, and parents, is described in detail by Sequeira et al. (12) In brief, the intervention incorporated case management, access to a young adult diabetes clinic, and developmentally-tailored diabetes education. CC participants at the time of enrollment attended one of two pediatric clinics, and transferred to the young adult diabetes clinic during the 12-month study period. All LC participants established care at the young adult clinic at the time of study enrollment. The young adult clinic was newly-established prior to study implementation, and did not undergo any major structural or staffing changes during the time of the study. It remains in operation as an ongoing clinical service at the County Hospital, where patients can be followed continually until approximately age 30. Participants received developmentally-tailored diabetes education at each quarterly clinic visit. Case managers at each site, who had bachelor's or Master's degrees in public health and previous experience in project coordination for clinical research, facilitated delivery of the educational materials, assisted CC participants in transferring from the pediatric to adult clinic, guided all participants in public insurance enrollment to become eligible for medical visits, and encouraged participants' adherence to scheduled clinic visits. The amount and frequency of case management varied depending on the needs of each participant. All participants received reminder calls for their clinic appointments and follow-up as needed to ensure their clinic attendance. Case management also involved, on an as-needed basis, assisting LC and CC participants with health care coverage applications and renewals, assistance filling prescriptions at the County pharmacy, making and rescheduling clinic appointments, following up on clinical referrals for specialty care, and navigating the healthcare system. Finally, all participants had access to group carbohydrate counting classes and a private social networking website, although uptake of these two intervention components was quite low. Only 3 CC and 5 LC participants attended a carbohydrate counting class; while a few participants created accounts for the private social networking website, there were, unfortunately, no ongoing interactions among participants on the site.

All data were analyzed using SAS for Windows, version 9.4 (SAS Institute, Cary, N.C.). All p-values are two-sided. Baseline characteristics of the LC and CC groups were compared using independent sample t-tests or Fisher's exact tests as appropriate. Healthcare utilization measures over the 12-month period were compared using Fisher exact tests for emergency department visits, hospitalizations, and incidents of severe hypoglycemia (yes for one or more vs. no), and negative binomial regression for number of routine clinic visits. Change scores for A1C and measures of health and psychosocial measures were calculated by

subtracting the baseline value from the 12-month value for all participants who had a 12month measurement. A1C was compared by changes in values from baseline to 12 months, and linear trend from baseline to 12 months. Change values were analyzed using independent sample t-tests. Overall monthly rates of change were compared using mixed effects regression models, with statistical significance of the interaction term (treatment group*time) indicative of difference in trends over time in the two groups. Psychosocial outcomes were compared in the LC vs. CC at baseline and 12 months using independent sample t-tests. Changes within each of the groups in these outcomes over the 12-month study period were assessed using paired samples t-tests, and changes from baseline to 12 months were compared for LC vs. CC using independent sample t-tests.

Results

Baseline characteristics

Fifty-one participants enrolled in the CC, and 24 participants in the LC. Among LC participants, 19 (79%) had previously received care at one of the two pediatric study sites where CC participants were recruited. Table 1 summarizes baseline demographic data for CC and LC participants. LC participants reported a mean lapse in routine diabetes care of 11.6 months. In comparing the two groups, LC participants were older (p<0.0001), less likely to live with family (p=0.01), and had a longer duration of diabetes (p=0.05) compared to CC participants. They were less likely to report receiving diabetes medications from their current provider, versus a previous provider, not having a prescription, or other (p<0.0001). They were more likely than CC participants to report running out of, or being unable to afford, diabetes supplies (p=0.001 for both).

Loss to follow-up differed between the CC and LC participants. With respect to follow-up at the study's clinical sites (pediatric and young adult diabetes clinics), 84.3% (n=43) of CC participants and 62.5% (n=15) of LC participants maintained continuity of care and thus had 12-month outcome data available for routine medical visits and A1C values. However, only 72.5% (n=37) of CC participants and 45.8% (n=11) of LC participants completed their 12-month study visit, where other healthcare utilization and psychosocial outcomes were assessed. In each case, loss to follow-up was significantly higher among LC participants than CC participants (p=0.04 for both).

Of the 9 LC participants who did not maintain continuity of care at the study's clinical sites, 3 obtained private insurance during the study and were no longer eligible to receive care at the clinic, two voluntarily transferred to other providers, one was incarcerated during the study period, and three were lost to follow-up. Comparing baseline characteristics for these 9 participants versus the 15 who maintained care at the study's clinical sites, participants lost to follow-up had different work situations, with a greater proportion not working (67% vs. 27%), versus working part-time or full-time (p=0.03). They were also more likely to report having missed social activities due to diabetes (50% vs. 6.7%, p=0.03). There were no other significant differences between LC participants who completed the study versus those lost to follow-up (data not shown).

Healthcare utilization

Table 2 summarizes participants' healthcare utilization at baseline and during the 12 month intervention period. With respect to routine diabetes care over the 12-month study period, there were no differences in the average number of clinic visits between CC and LC participants (p=0.23). At baseline, a greater proportion of LC as compared to CC participants reported emergency department visits in the previous 3 months (p=0.004). At 6 and 12 months, there was no significant difference in the proportion of participants reporting emergency department visits (p=0.06 and p=0.22 respectively). There were no significant differences in the proportion of participants at baseline (p=0.10), 6 months (p=0.16), or 12 months (p=0.12).

Clinical outcomes

Table 3 summarizes participants' glycemic control and incidence of severe hypoglycemia. At baseline, a greater proportion of LC participants as compared to CC participants reported severe hypoglycemia within the previous 3 months (p=0.005). At both 6 and 12 months, there was no difference in the proportion of CC versus LC participants reporting severe hypoglycemia (6 months: p=0.38; 12 months: p-value not calculable). With respect to glycemic control, at baseline LC participants had a higher A1C (10.9%) than CC participants (9.4%; p=0.005), and this between-group difference persisted at 6 and 12-month follow-up (p=0.002 and p=0.02 respectively). However, over the 12-month study period, both groups lowered their A1C; CC participants by 0.40% (p=0.03) and LC participants by 0.77% (p=0.02). The magnitude of change in A1C was not significantly different between groups (p=0.28). Finally, while substantial missing data in the CC group prohibits direct between-group comparisons, the proportion of LC participants who reported ever running out of supplies decreased from 58.3% to 36.4% (p=0.29) and the proportion of LC participants who were unable to afford supplies remained stable (58.3% at baseline, 54.5% at 12-month follow-up; p=1.00).

Psychosocial outcomes

Table 4 summarizes participants' changes in psychosocial variables from baseline to 12 months. LC participants reported higher levels of depressive symptoms than CC participants at both baseline (p=0.05) and 12 months (p=0.10). At baseline 29% of LC participants were above the threshold for likely major depression (PHQ-9 score 10), compared to 10% of CC participants (p=0.05). At 12 month follow-up, the percentage of LC participants above the threshold had decreased slightly to 27% while the percentage of CC participants had increased slightly to 14%, such that the difference between the groups was no longer statistically significant (p=0.36). At 12 months, CC participants had improved global well-being (GWB; 24-hour GWB p=0.04, monthly GWB 0.006), perceived stress (p=0.0005), and diabetes knowledge (p=0.002). LC participants did not improve on any psychosocial outcomes at 12 months, and had lower overall life satisfaction than at baseline (p=0.007). When considering changes in psychosocial outcomes over the course of the study, the only between-group difference was in overall life satisfaction (p=0.003), which improved for CC participants and deteriorated for LC participants.

Discussion

This study examined clinical, psychosocial, and healthcare utilization outcomes following exposure to a transition intervention among young adults with type 1 diabetes who had experienced lapses in care following discharge from pediatric care, as compared to young adults who had continual access to care, and transition support, during their transfer from pediatric to adult healthcare. The study's strengths include its recruitment of a high proportion of socioeconomically disadvantaged and ethnic minority participants, and engagement of a highly vulnerable group of young adults who had been previously lost to follow-up in routine clinical care. During the 12-month intervention period, both groups of participants maintained a similar frequency of routine diabetes care visits, and both groups improved their glycemic control. Participants with a history of lapses in care also decreased their incidence of hypoglycemia and emergency department utilization over the study period. However, these participants also had higher levels of depressive symptoms throughout the study period than those with continual access to care, and their life satisfaction declined over their 12 months of study participation. Thus, overall, the intervention offered to participants with a history of lapsed care may have improved these participants' clinical and healthcare utilization outcomes, while their psychosocial difficulties persisted. Patients who presented to referring clinics with a history of severe hypoglycemia or frequent emergency department utilization may have been more likely to have been referred to the study than patients without these concerns. People recruited with extreme values are likely to show regression to the mean in subsequent measurements, however, the difference in this phenomenon between the CC and LC groups would likely be minimal.

While the CC group reported modest improvements in psychosocial outcomes, the LC group reported a decrease in overall life satisfaction. Additionally, LC participants had higher depressive symptoms than CC participants throughout the study period. Given that the intervention evaluated in this study did not include a psychosocial component (aside from referrals to mental health providers during the routine provision of clinical care), this suggests that the access to care and tailored diabetes education offered by the study were not sufficient in themselves to improve LC participants' psychosocial well-being. Given our previous research documenting the significant psychosocial challenges encountered by the LC group and their relationship to glycemic control (13), and physicians' limited capacity to address many of these challenges in routine care (21), future interventions for this population should incorporate a component to address psychosocial well-being.

The higher rate of loss to follow-up in the LC group belies this group's vulnerability to gaps in care. We initially hypothesized that LC participants' loss to follow-up may be due to chronic, ongoing life stressors which make continuity of care more difficult to maintain, as our team previously found that these life stressors were associated with their duration of lapse in care at baseline (13). However, we found no such relationship between the number of psychosocial stressors reported at baseline and loss to follow-up during the study period (p=0.56). This may be because only three of the 24 LC participants were truly lost to follow-up with respect to clinical care; the remaining LC participants transferred care elsewhere, or were unable to be reached during the interval when 12-month outcome data were collected,

but maintained continuity of care at the young adult clinic. Thus, this group was not truly equivalent to those who had been lost to follow-up before study enrollment.

As the majority of LC participants received pediatric diabetes care from the same clinics as CC participants, it is likely that factors other than their clinical care were the main reasons for their loss to follow-up, although it is also possible that the CC participants may have encountered similar challenges in the absence of the LEAP intervention. However, anecdotes from the LEAP case managers, and qualitative interviews with LC participants, revealed a diversity of issues contributing to LC participants' loss to follow-up both prior to and during the study period. These challenges belie a single explanation or model of intervention, ranging from a longstanding history of complex psychosocial issues such as mental illness, homelessness, or substance abuse to more straightforward barriers such as lack of knowledge regarding insurance enrollment, miscommunications between patients and providers, or temporary logistical barriers that contributed to lapses in care (13, 21).

Given the wide range of challenges contributing to loss to follow-up among this population, the need for case management and psychosocial services to address these challenges varies considerably. For example, financial and logistical issues were the primary barriers to care among some participants, which may benefit from intensive case management and provision of resources. For others, mental health concerns may be the more significant barrier to care, requiring coordinated care among medical and behavioral health providers. Further research is needed to identify what issues can be prevented or resolved at different levels of care, and develop best practices for providing appropriate resources to patients. Ultimately, a stepped care or adaptive intervention model for transition, with service delivery tailored according to individual patients' needs, is likely the best strategy to facilitate continuity of care while conserving resources. In addition to clinical supports and services, this population may benefit from further research and intervention development related to family and social support. For example, the greater proportion of CC participants as compared to LC participants who lived with family may represent a protective factor which facilitated better outcomes. Future research which explores social supports available to vulnerable populations, and seeks to bolster naturally-occurring support for chronic disease management, may be a fruitful direction for future research.

Limitations

This study has several significant limitations. First, the study's sample sizes were small, and therefore our statistical tests lacked sufficient power to evaluate between-group differences in many outcomes; thus these findings should be viewed as preliminary and repeated in larger studies. The significant loss to follow-up, particularly in the LC, should also lead to caution in interpreting the findings. This is especially true for the study's self-reported outcomes: emergency department visits, hospitalizations, and the psychosocial outcomes presented in Table 4, as these variables had a higher proportion of missing data than did participants' routine clinic visits and A1C values, which were extracted from medical charts. In addition, some participants transferred care outside the study's clinical sites, leading to missing data regarding the number of routine clinic visits and A1C values. Finally, the LC and CC groups differed in several significant ways at baseline, most notably by being in

different stages of transition at the time of study enrollment. Furthermore, we did not assess the LC group's level of preparation for transition as part of the study, and thus cannot determine the extent to which their preparation differed from that of the CC group. We did not adjust our analyses for baseline demographic characteristics or clinical values. As such, our results are not meant to document the effect of lapse in care, but rather to characterize intervention outcomes among a lapsed-care sub-population in contrast to its continuous-care counterpart.

Implications and Contribution

In this study, case management and developmentally appropriate healthcare improved clinical outcomes among young adults with previous lapses in care. However, psychosocial issues and continuity of care remain substantial challenges. Strategies to identify high-risk individuals and maintain continuous care throughout young adulthood require further research to improve health and wellbeing.

Acknowledgments

The authors gratefully acknowledge Magaly Juarez (Keck School of Medicine of University of Southern California, Los Angeles, CA), who was research staff and helped with recruitment, retention, patient education, and survey administration; and Marisa Cohen (Children's Hospital of Los Angeles, Los Angeles, CA), who was research staff and helped with recruitment, retention, and survey administration. Parts of this study were presented in abstract form at the 73rd Scientific Sessions of the American Diabetes Association, Chicago, IL, 21–25 June 2013. This project was supported by the Helmsley Type 1 Diabetes Transition LEAP Program (Leona M. and Harry B. Helmsley Charitable Trust #2010PG-T1D011, principal investigator A.L.P.) and the National Center for Advancing Translational Sciences, National Institutes of Health (KL2-RR-031991, principal investigator T. Buchanan).

This study was funded by the Leona M. and Harry B. Helmsley Charitable Trust. The study sponsor did not have any role in the study design; collection, analysis, and interpretation of data; writing of the report; or decision to submit the manuscript for publication. EAP wrote the first draft of the manuscript. No honorarium, grant, or other form of payment was provided to anyone to produce the manuscript.

Abbreviations

A1C	hemoglobin A1C
ADA	American Diabetes Association
AIOS	Arizona Integrative Outcomes Scale
CC	Continuous Care
DES-SF	Diabetes Empowerment Scale-Short Form
DKT	Diabetes Knowledge Test
GWB	Global Well-Being
LC	Lapsed Care
LEAP	Let's Empower and Prepare
PHQ-9	Perceived Health Questionnaire-9
PSS	Perceived Stress Scale

SWLS Satisfaction with Life Scale

References

- Park MJ, Scott JT, Adams SH, et al. Adolescent and young adult health in the United States in the past decade: little improvement and young adults remain worse off than adolescents. J Adolesc Health. 2014; 55(1):3–16. [PubMed: 24815958]
- Stroud C, Walker LR, Davis M, Irwin CE Jr. Investing in the health and well-being of young adults. J Adolesc Health. 2015; 56(2):127–9. [PubMed: 25620297]
- 3. Beresford B, Stuttard L. Young adults as users of adult healthcare: experiences of young adults with complex or life-limiting conditions. Clin Med. 2014; 14(4):404–8.
- Hargreaves DS, Greaves F, Levay C, et al. Comparison of health care experience and access between young and older adults in 11 high-income countries. J Adolesc Health. 2015; 57(4):413–20. [PubMed: 26205758]
- Peters A, Laffel L. 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(11):2477–85. [PubMed: 22025785]
- Garvey KC, Wolpert HA, Rhodes ET, et al. Health care transition in patients with type 1 diabetes: Young adult experiences and relationship to glycemic control. Diabetes Care. 2012; 35(8):1716–22. [PubMed: 22699289]
- 7. Lyons SK, Becker DJ, Helgeson VS. Transfer from pediatric to adult health care: effects on diabetes outcomes. Pediatr Diabetes 4(1):19–23. 2014; 15(1):10–7.
- Garvey KC, Wolpert HA, Laffel LM, et al. Health care transition in young adults with type 1 diabetes: barriers to timely establishment of adult diabetes care. Endocr Pract. 2013; 19(6):946–52. [PubMed: 23807526]
- Miller KM, Foster NC, Beck RW, et al. Current state of type 1 diabetes treatment in the U.S.: Updated data from the T1D Exchange Clinic Registry. Diabetes Care. 2015; 38(6):971–8. [PubMed: 25998289]
- 10. Hendricks M, Monaghan M, Soutor S, et al. A profile of self-care behaviors in emerging adults with type 1 diabetes. Diabetes Educ. 2013; 39(2):195–203. [PubMed: 23396184]
- Johnson B, Elliott J, Scott A, et al. Medical and psychological outcomes for young adults with Type 1 diabetes: no improvement despite recent advances in diabetes care. Diabet Med. 2014; 31(2):227–31. [PubMed: 23952498]
- Sequeira PA, Pyatak EA, Weigensberg MJ, et al. Let's Empower and Prepare (LEAP): Evaluation of a structured transition program for young adults with type 1 diabetes. Diabetes Care. 2015; 38(8):1412–9. [PubMed: 25906787]
- Pyatak EA, Sequeira PA, Whittemore R, et al. Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with Type 1 diabetes. Diabet Med. 2014; 31(12): 1615–24. [PubMed: 24798586]
- Anderson RM, Fitzgerald JT, Gruppen LD, et al. The Diabetes Empowerment Scale-Short Form (DES-SF). Diabetes Care. 2003; 26(5):1641–2.
- 15. Fitzgerald JT, Funnell MM, Hess GE, et al. The reliability and validity of a brief diabetes knowledge test. Diabetes Care. 1998; 21(5):706–10. [PubMed: 9589228]
- Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. J Health Soc Behav. 1983; 24(4):385–96. [PubMed: 6668417]
- Nguyen-Rodriguez ST, Unger JB, Spruijt-Metz D. Psychological Determinants of Emotional Eating in Adolescence. Eating Disorders. 2009; 17(3):211–24. [PubMed: 19391020]
- Kroenke K, Spitzer RL. The PHQ-9: A new depression diagnostic and severity measure. Psychiat Ann. 2002; 32(9):509–15.
- Diener E, Emmons RA, Larsen RJ, Griffin S. The Satisfaction With Life Scale. J Pers Assess. 1985; 49(1):71–5. [PubMed: 16367493]

- Bell IR, Cunningham V, Caspi O, et al. Development and validation of a new global well-being outcomes rating scale for integrative medicine research. BMC Complement Altern Med. 2004; 4(1)
- Pyatak EA, Sequeira P, Peters AL, et al. Disclosure of psychosocial stressors affecting diabetes care among uninsured young adults with type 1 diabetes. Diabet Med. 2013; 30(9):1140–4. [PubMed: 23758145]

Table 1

Baseline participant characteristics.

Variables	Continuous Care (n=51) Mean (SD), N (%)	Lapsed Care (n=24) Mean (SD), N(%)	P value ^a
	Demographic characteristics		
Age	19.61 (1.02)	21.04 (1.04)	<.0001
Gender			.62
Female	25 (49.02)	10 (41.67)	
Male	26 (50.98)	14 (58.33)	
Race/Ethnicity			.33
Hispanic	33 (64.71)	17 (70.83)	
Non-Hispanic	18 (35.29)	7 (29.17)	
White	5 (9.80)	1 (4.17)	
Black	5 (9.80)		
Other	8 (15.69)	6 (25.00)	
Birthplace			.13
US	47 (92.16)	19 (79.17)	
Other	4 (7.84)	5 (20.83)	
Living situation			.01
With family	43 (84.31)	13 (54.17)	
Other	8 (15.69)	11 (45.83)	
Education			.19
<hs< td=""><td>8 (15.69)</td><td>4 (16.67)</td><td></td></hs<>	8 (15.69)	4 (16.67)	
HS grad or GED	27 (52.94)	16 (66.67)	
some college	14 (27.45)	2 (8.33)	
trade school/2-year degree	2 (3.92)	2 (8.33)	
BA/BS	0 (0.00)	0 (0.00)	
Parents Education			.26
<hs< td=""><td>20 (39.22)</td><td>2 (8.33)</td><td></td></hs<>	20 (39.22)	2 (8.33)	
HS grad or GED	15 (29.41)	7 (29.17)	
Some college/2-year degree	10 (19.61)	5 (20.83)	
BA/BS/advanced degree	4 (7.84)	4 (16.67)	
Don't know	2 (3.92)	6 (25.00)	
	Clinical characteristics		
Health insurance status			.12
Private insurance ^b	1 (1.96)	0 (0)	
Publicly-funded healthcare $^{\mathcal{C}}$	43 (84.31)	24 (100.00)	
Don't know	7 (13.73)	0 (0)	

Variables	Continuous Care (n=51) Mean (SD), N (%)	Lapsed Care (n=24) Mean (SD), N(%)	P value ^a
Duration of diagnosis	9.61 (3.91)	11.67 (4.60)	.05
Duration of lapse in care (months)	_	11.58 (9.65)	_
Where prescription meds obtained			<.0001
Current provider	49 (96.08)	3 (12.50)	
Previous provider	2 (3.92)	8 (33.33)	
Other		6 (25.00)	
Don't have prescription		7 (29.17)	
Ever run out of supplies?			.001
Yes	10 (19.61)	14 (58.33)	
No	41 (80.39)	10 (41.67)	
Ever unable to afford supplies?			
Yes	9 (17.65)	14 (58.33)	.001
No	42 (82.35)	10 (41.67)	
Missed school/work due to diabetes			.16
Yes	5 (10.00)	6 (25.00)	
No	45 (90.00)	18 (75.00)	
Missed social activities due to diabetes			.31
Yes	6 (12.00)	5 (21.74)	
No	44 (88.00)	18 (78.26)	

 $^{a}_{\mbox{t-test}}$ for age, duration of diagnosis and duration of lapse in care; Fisher exact test for all others

^CPublic programs only (e.g. MediCal, California Children's Services) or uninsured

Comparison of healthcare utilization.

	Continu	ous Care Group	Lapse	l Care Group	
Type of event	Number Y/N	Mean (SD) # of visits	Number Y/N	Mean (SD) # of visits	P value ^a
Routine clinic visits over the 12-month study period		3.04 (1.14)		2.63 (1.47)	.23
Baseline					
ED Visit	5/46	0.12 (0.38)	10/14	0.63 (0.97)	.004
Hospitalizations	6/45	0.12 (0.36)	7/17	0.46 (0.83)	.10
6 months					
ED Visit	2/42	0.05 (0.21)	4/15	0.21 (0.42)	.06
Hospitalizations	2/42	0.05 (0.21)	3/16	0.16 (0.37)	.16
12 months					
ED Visit	2/35	0.05 (0.23)	2/9	0.36 (0.92)	.22
Hospitalizations	1/37	0.03 (0.16)	2/9	0.36 (0.92)	.12
2					

¹Between-group comparisons: Fisher exact test for occurrence (yes/no) of one or more ED visits and hospitalizations; negative binomial regression for number of routine clinic visits.

Comparison of clinical outcomes.

	Č	ontinuous Care Group		Lapsed Care Group	P-value
AIC		Mean (SD)		Mean (SD)	Chi squared or t-test
Baseline (n=75)		9.4 (2.1)		10.9 (2.2)	.005
6 months (n=55)		9.1 (1.8)		10.7 (2.0)	.002
12 months (n=58)		9.1 (2.0)		10.5 (2.2)	.02
Change from baseline to 12 months (n=58)		-0.395 (1.16)		-0.767 (1.07)	.28
P-value for change from baseline to 12 months		0.03		0.02	
Average rate of change in A1C per month *		-0.03		-0.05	.42
Severe Hypoglycemia	Number Y/N	Mean (SD) # of reported incidents	Number Y/N	Mean (SD) # of reported incidents	Fisher exact test
Baseline	2/49	0.12 (0.47)	7/17	0.33 (0.56)	.005
6 months	3/48	0.06 (0.24)	3/21	0.13(0.34)	.38
12 months	0/37	0.0(0.0)	0/11	0.0 (0.0)	n/a

Average rate of change calculated using mixed effects regression models

Table 4

Changes in psychosocial variables from baseline to 12 months

		Continuous Ca	rre Group		Lapsed Car	e Group	
Variables	u	Mean(SD)	from baseline p value	u	Mean(SD)	from baseline p value	Between-group P value
Global Wellbeing (past 24 hours)							
Baseline	51	72.69 (20.35)		24	76.54 (17.24)		0.43
12 months	37	82.43 (18.96)		11	70.00 (19.49)		0.06
Change	37	8.32 (24.32)	0.04	11	0.18 (16.25)	0.97	0.30
Global Wellbeing (past month)							
Baseline	51	69.88 (22.36)		24	71.54 (22.31)		0.77
12 months	37	82.41 (16.97)		11	71.27 (15.15)		0.06
Change	37	11.11 (23.04)	0.006	11	0.45 (24.41)	0.95	0.19
Diabetes Empowerment							
Baseline	51	33.06 (6.07)		24	33.04 (4.09)		0.98
12 months	37	34.32 (6.24)		11	32.27 (3.26)		0.16
Change	37	0.78 (7.54)	0.53	11	0.00 (3.71)	1.00	0.64
Life Satisfaction							
Baseline	51	24.43 (6.54)		24	23.75 (5.83)		0.66
12 months	37	26.22 (6.69)		11	20.55 (6.41)		0.02
Change	37	1.35 (6.51)	0.21	11	-3.45 (3.36)	0.007	0.003
Perceived Stress							
Baseline	51	46.08 (8.55)		24	46.38 (7.52)		0.88
12 months	37	39.49 (9.32)		11	45.55 (10.35)		0.07
Change	37	-5.51 (8.72)	0.0005	11	-2.55 (8.38)	0.34	0.32
Diabetes Knowledge							
Baseline	51	10.92 (1.65)		24	11.17 (1.63)		0.55
12 months	37	11.62 (1.36)		11	11.55 (1.51)		0.87
Change	37	0.62 (1.11)	0.002	11	0.45 (1.75)	0.41	0.77

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Variables	u	Mean(SD)	from baseline p value	u	Mean(SD)	from baseline p value	Between-group P value
Depression (mean score)							
Baseline	51	4.31 (3.90)		24	6.96 (5.64)		0.05
12 months	37	4.57 (4.66)		11	7.27 (4.73)		0.10
Change	37	0.51 (4.34)	0.48	11	0.00 (5.02)	1.00	0.74
Depression (% above clinical cutpoint)	Yes	No		Yes	No		
Baseline	5 (9.8%)	46 (90.2%)		7 (29.2%)	17 (70.8%)		0.05
12 months	5 (13.5%)	32 (86.5%)		3 (27.3%)	8 (72.7%)		0.36