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Ready or not? Greater readiness for independent self-care predicts better self-management but not HbA1c in teens with type 1 diabetes

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Abstract

OBJECTIVE ––—Prior to the transfer from pediatric to adult health care transition, teens with type 1 diabetes seek increasing independence in diabetes self-care while parent involvement in care decreases. Yet, few teens attain glycemic targets. This study aimed to assess changes in perceived readiness for independent self-care in teens with type 1 diabetes over 18 months, from both teens' and parents' perspectives, and to evaluate its predictive value for diabetes self-management and hemoglobin A1c (HbA1c).

RESEARCH DESIGN AND METHODS ––—At baseline, 6, 12, and 18 months, 178 teens with type 1 diabetes (mean±SD age 14.9±1.3 years; HbA1c 8.5±1.0% (69±11 mmol/mol); 48% female) and their parents completed the Readiness for Independent Self-Care Questionnaire (RISQ-T and RISQ-P, respectively) and a measure of self-management. Chart review provided HbA1c values. Statistical analyses encompassed bivariate correlations, paired t-tests, and multivariable longitudinal mixed models.

RESULTS ––—Teens perceived greater self-care readiness than their parents at baseline and over 18 months of follow-up. Both teen and parent perceptions of teen readiness for independent self-care increased over time, and significantly predicted higher teen self- and parent proxy-reported teen diabetes self-management respectively, but not improved HbA1c.

CONCLUSIONS ––—The current findings may point to a disconnect between how increased readiness for independent self-care may translate into better perceived diabetes self-management, but not into better HbA1c. In an effort to optimize HbA1c in teens with type 1 diabetes, future

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Author Contributions

E.R.G. analyzed the data, interpreted the results, and wrote the manuscript. L.T. interpreted the results and edited the manuscript. L.K.V. and L.M.L. collected the data, analyzed the data, interpreted the results, and edited the manuscript. L.M.L. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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Duality of Interest

We have no relevant conflict of interest to disclose.

research is needed to design interventions that align perceived readiness for independent self-care with self-care behaviors that improve HbA1c.

Keywords

type 1 diabetes; self-management; transition; readiness; adolescents; glycemic control

INTRODUCTION

Adolescence is a precarious developmental phase in the lives of persons with type 1 diabetes. Extensive research has shown that teens with type 1 diabetes often exhibit declining diabetes self-management coinciding with decreasing parent involvement in diabetes management tasks (1). At this point in their lives, few teens have embraced diabetes self-care and integrated their illness into their identity (2). Therefore, it is not surprising that the majority of teens do not attain glycemic targets (3). During the stage of adolescent growth and development, there is a gradual shift from parent-driven diabetes management to adolescent-driven self-care (4–9). Teens naturally seek and assume increasing independence in multiple areas of life, such as their academics and socialization, and it becomes increasingly necessary that they become independent in their diabetes self-care behaviors, given that they are often physically apart from their parents and parental involvement in their diabetes management naturally declines (8–10). This shift may account for some of the recognized decline in diabetes self-management and the deteriorating glycemic control that occurs in this age group.

There remains a need to judiciously assess if and when (or whether) teens are ready to accept and carry-out their diabetes self-care. Both parents and clinicians could benefit from a better understanding of teens' readiness for self-care throughout adolescence. Readiness for independent self-care can be considered an important clinical determinant of self-management behaviors in teens with type 1 diabetes, and a necessary precursor to a successful transfer from pediatric to adult health care systems. The process of transition in care during adolescence entails the gradual acquisition of diabetes self-care tasks by teens, as during childhood most, if not all, of diabetes management rests with parents. There has been substantial interest in the transfer of diabetes care from pediatric providers to adult health care settings due to deficiencies in the process related to gaps in care and deteriorating glycemic control in older adolescents and young adults (11; 12). Part of these deficits may stem from inadequate acquisition of diabetes self-care tasks during the adolescent years, resulting in teens being insufficiently ready to gradually take on their self-care tasks in a more independent manner. Readiness for independent self-care has previously been defined as including gaining greater knowledge of the importance of diabetes self-management and the ability to independently manage the multiple daily diabetes self-care tasks. Furthermore, the acquisition of this knowledge and these skills needs to be aligned with a teen's awareness of the importance of self-care for their health (9). Thus, health care teams need to assess teen readiness for independent self-care in order to identify those teens with type 1 diabetes who may require greater education and support in order to optimize glycemic control prior to transfer to adult health care. To that end,

our research group has recently developed and validated the Readiness for Independent Self-Care Questionnaires, RISQ-T (teen self-report) and RISQ-P (parent proxy-report) (9).

In a large sample of teens with type 1 diabetes and their parents, the current longitudinal study aimed to assess changes in perceived readiness for independent self-care in teens with type 1 diabetes over time, from both teen and parent perspectives, using the RISQ-T and the RISQ-P, respectively. Our primary aim was to evaluate the predictive value of readiness for independent self-care for teen diabetes self-management and HbA1c.

RESEARCH DESIGN AND METHODS

Design and Sample

The current report is part of a longitudinal study aimed at enhancing self-care behaviors around blood glucose monitoring and insulin administration in teens with type 1 diabetes. Efforts to encourage self-care included motivational interviewing with problem-solving strategies around these two self-care behaviors as well as text messaging to remind teens to check blood glucose levels at pre-determined, self-selected times. Participants were randomized at baseline to one of four groups using a 2×2 factorial design: text message group, problem-solving group, text message + problem-solving group, and control group (neither text message nor problem-solving). These results have been previously published, with the observations that the interventions did not impact glycemic outcomes (13). The research team recruited teens at two tertiary pediatric diabetes centers in the U.S. However, in accordance with study procedures, teens and parents at only one of the two sites completed the RISQ-T and RISQ-P. Thus, participants from only one of the sites are included in this report. Inclusion criteria included: 13 to 17 years old, type 1 diabetes for at least six months, insulin dose ≥ 0.5 U/kg/day, HbA1c 6.5–11.0%, and fluency in English. Exclusion criteria included significant developmental or cognitive disorder or a diagnosed major psychiatric disorder (e.g., diagnosed eating disorder), and other psychosocial, medical or family issues, as assessed by the teen's health care team, that would prevent study participation. Research assistants contacted the parents of potentially eligible teens identified through medical record review and provider referrals by phone or in-person on the day of a clinic appointment. Families could also contact study staff in response to approved recruitment materials (flyers posted in clinic, information in clinic newsletter) (13). All participating teens and their parents provided written informed assent and consent, respectively. Teens and parents received modest monetary compensation for completing surveys. The study protocol was approved by the Institutional Review Board prior to implementation of any study procedures.

Data Collection and Measures

Data were collected through teen-parent interview, teen-reported measures, parent-reported measures, and review of the electronic health record. Most study visits occurred on the same days as clinic appointments. The following measures were obtained every 6 months over an 18-month period, providing 4 data points: baseline, 6, 12, and 18 months.

Readiness for Independent Self-Care Questionnaire—The Readiness for Independent Self-Care Questionnaires, RISQ-T (teen self-report) and RISQ-P (parent proxy-report), are two newly developed and validated self-report questionnaires assessing perceived readiness for independent diabetes self-care of teens with type 1 diabetes (9). In the 20-item RISQ-T, three domains are assessed: 1) Knowledge (5 items reflecting knowledge required to engage in effective self-care, e.g., "*I know how to determine my insulin dose based on my blood sugar"*), 2) Behavior (10 items reflecting frequency of independent self-management behaviors, e.g., *"I adjust my insulin and/or food intake for exercise"*), and 3) Perceived Importance (5 items reflecting adolescents' perceptions of the importance of these behaviors, e.g., *"To take care of my diabetes on my own, it is important for me to know/learn how to interpret blood sugar information"*). The 15-item RISQ-P includes the Knowledge and Behavior domains, assessed from the parents' perspectives; the Perceived Importance domain of the RISQ-T is not included in the RISQ-P. Response options for the Knowledge domain are "No/Yes" (scored 0/4). Response options for the Behavior and Perceived Importance domains are on 5-point Likert scales: 0="Never" to 4="Always", and 0="Not important" to 4="Very important", respectively. For each domain and for the full survey, a total score is calculated by calculating the mean of all non-missing items and multiplying this value by 25 to normalize the total score to a scale of 0–100, with higher scores indicating greater perceived teen readiness for independent self-care.

Diabetes Management Questionnaire—The validated Diabetes Management Questionnaire (DMQ; (14)) assesses teen adherence for diabetes management tasks over the previous month, by both teen and parent report. Items include tasks related to insulin administration, physical activity, dietary management, and blood glucose monitoring. Both versions of the measure consist of 20 items with 5-point Likert response options, ranging from "almost never" to "almost always." Total scores are calculated by calculating the mean of all non-missing items and multiplying this value by 25 to normalize the total score to a scale of 0–100, with higher scores indicating greater adherence. Both teen and parent measures demonstrate strong psychometric properties as previously reported (14).

Glycemic Control—Each teen provided blood for hemoglobin A1c (HbA1c) assay as part of routine clinical care, measured by the Roche Cobas Integra (Roche Diagnostics, Indianapolis, IN, Ref. range: 4%–6% [20–42 mmol/mol]).

Statistical Analyses

To start with, for participants with missing HbA1c at 18 months (n = 8), we carried forward the most proximal HbA1c value after the baseline measurement (n = 3) or excluded participants from the longitudinal analyses if they had no follow-up HbA1c data beyond baseline (n = 5). Similarly, for participants with missing RISQ-T or RISQ-P scores at 18 months (n = 7, and n= 7, respectively), we carried forward the most proximal RISQ-T or RISQ-P value after the baseline measurement (n = 4, and n = 5, respectively) or excluded participants from the longitudinal analyses because of lacking follow-up RISQ-T or RISQ-P values after the baseline measurement (n = 3, and n = 2, respectively). With regard to the statistical analyses, descriptive statistics are presented as mean±SD for continuous data and as percentages for categorical data. Paired t-tests assessed differences

between teen self-reports and parent proxy-reports of the study measures. Changes in study measures from baseline to 18 months were also assessed by paired t-tests and confirmed by longitudinal mixed models. For the primary analyses related to associations between changes in teen readiness for independent self-care and diabetes self-management behaviors and glycemic control, we constructed multivariable longitudinal mixed models, adjusted for salient demographic and diabetes-specific factors. These covariates were included in the models based upon their known predictive value and clinical relevance for self-management and glycemic control, and included age, sex, diabetes duration, and intervention group assignment. Given the fact that we are assessing change over time, we included a time variable (i.e., the number of months since baseline) in the model. In the models predicting glycemic control, we also added teen self-management as a predictor. More specifically, in one set of models for the teen and parent reports, readiness for independent self-care (RISQ) and diabetes self-management (DMQ) were both included, and in a second set of models, only diabetes self-management (DMQ) report was included. We performed these analyses separately for teen self- and parent proxy-reports, resulting in four models (teen self- and parent proxy-reported measures predicting teen self- and parent proxy-reported teen self-management, respectively, and teen self- and parent proxy-reported measures predicting HbA1c). Data analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC).

RESULTS

Baseline Sample Characteristics

Table 1 presents demographic and diabetes-related characteristics of the sample (N=178). The teens (48% female, 88% non-Hispanic white) had a mean age of 14.9±1.3 years (range 13.0–17.5 years). Mean diabetes duration was 7.4±3.7 years, and the sample had a mean HbA1c of 8.5±1.0% (69±11 mmol/mol) and performed BG monitoring 4.9±2.0 times daily; the majority of teens (67%) received insulin pump therapy. At baseline, RISQ-T scores were higher than RISQ-P scores ($p<0.001$), indicating that teens rated their behaviour, knowledge, and perceived importance of self-care tasks related to readiness for independent self-care higher than their parents (see Table 2). Teen scores remained significantly higher than the parent scores, even when the Importance domain on the RISQ-T was not included. With respect to self-reported adherence in diabetes management, the teens and parents reported similar baseline scores on the DMQ.

Readiness for Independent Self-care, Adherence, and HbA1c over Time

From baseline to 18 months, there were significant increases in both teen and parent perceptions of teen readiness for independent self-care (teen: $t(170)=5.69$, $p<0.001$, parent: $t(170)=4.37$, $p<0.001$). In contrast, both teens and parents reported declining levels of teen diabetes self-management (DMQ scores) over the 18-month study period (teens: $t(166)= -3.97$, $p<0.001$, parents: $t(165)= -4.46$, $p<0.001$). There was no significant change in HbA1c over the study period (baseline HbA1c compared with 18-month HbA1c [$t(172)=1.21$, $p=0.23$]) (see Table 2).

In order to assess the predictive value of changes in teen readiness for independent self-care on teen diabetes self-management and glycemic control, we constructed longitudinal mixed

models separately for teen and parent reports. The models included the variables of teen age, duration of diabetes, sex, and study group assignment. In both the teen and parent models predicting teen self-management over 18 months, higher teen self-reported and parent proxy-reported teen readiness for independent self-care using the RISQ-T and RISQ-P, respectively, were associated with greater teen diabetes self-management by teen and parent DMQ reports (in both models $p<0.001$ for RISQ-T and RISQ-P). In other words, although overall scores for diabetes self-management declined over the 18 months, higher perceived readiness for self-care was related to higher diabetes self-management scores. Younger age was also significantly associated with higher scores for teen diabetes self-management over time in both models of teen- and parent-reported measures (all $p<0.001$).

Given that greater teen readiness for self-care was associated with greater teen self-management, the next question related to the factors associated with teen glycemic control over time. Separate models predicting HbA1c were constructed for the teen and parent reports, adjusting for the same co-variates as noted above, in addition to the measure of diabetes self-management, the DMQ. In one set of models for the teen and parent reports, readiness for independent self-care (RISQ) and diabetes self-management (DMQ) were both included, and in a second set of models, only diabetes self-management (DMQ) report was included. In separate models for teen and parent reports, greater teen self-management by teen-report and parent-report was related to lower HbA1c ($p=0.0004$ and $p<0.001$, respectively). However, neither teen-reported nor parent-reported teen readiness for independent self-care were related to HbA1c when included in the models. The parameter estimates of the association of diabetes self-management with HbA1c were similar in the models with and without inclusion of the RISQ, for both the teen and parent reports. No other covariates predicted HbA1c.

CONCLUSIONS

The current multi-informant study examined teen readiness for independent self-care at multiple time points over 18 months in a relatively large sample of teens with type 1 diabetes and their parents. We further sought to assess how teen and parent perceptions of teen readiness for independent self-care related to teen diabetes self-management and, in turn, to glycemic outcomes, assessed as HbA1c.

Over time, as teens in the study naturally grew older and gained maturity, both teens and their parents reported an increase in teens' readiness for independent self-care. Notably, teens consistently perceived themselves as more '*ready*' for independent self-care than their parents perceived them to be. Although there is limited research involving the novel concept of teen readiness for independent self-care (9), the increased self-reported perceptions of readiness aligns with developmental expectations. In contrast, both teens and parents reported decreasing teen diabetes self-management over time. Decreasing self-management in adolescence is well-documented in teens with type 1 diabetes (e.g.,(3; 15)), and HbA1c tends to rise during this developmental stage (3). Our study affirms this observation. Hence, it is not surprising that teens' HbA1c levels did not improve over the course of the 18-month study. However, there was no worsening in glycemic control, despite the fact that the mean

age was 16.5 at study's end, which was approaching the age at which the pinnacle of HbA1c occurs (3; 15).

Not unexpectedly, our findings revealed that greater teen and parent perceptions of teen self-care readiness predicted higher teen and parent reports of teen self-management. In turn, higher scores for teen self-management, as reported by both the teens and parents, predicted lower HbA1c or better glycemic control. Overall, however, teen self-management did not increase for the sample as a whole while reports of readiness for teen self-care did increase over time, as reported by both teens and parents. This incongruity seems to point to a disconnect between how '*ready'* teens and parents perceive teens to be in their self-care, and the actual diabetes self-care behaviors that are needed to optimize glycemic outcomes. Although teens might perceive themselves to be more ready to take on self-care tasks, they may not be able to translate this readiness immediately to improved self-care behaviors that would lead to more optimal glycemic control. This appears most evident on the older teens, given that age was indirectly related to higher reports of diabetes self-management. The competing demands of adolescence and young adulthood become more prominent during the older teen years and in the early twenties (16; 17).

The current study has some limitations that warrant future research. First, our study sample was relatively small, and may be considered quite homogeneous, as it consisted of mainly non-Hispanic white teens from 2-parent families, with a relatively high proportion of pump users. Further, as the study procedures took place at the time of the regular clinic visits, our study population may consist of a potentially more engaged cohort than families not regularly attending clinic, and with different baseline characteristics (e.g., health utilization rates, literacy levels etc.). In conjunction with recent attention for how social determinants of health such as socio-economic status, access to health care etc., affect diabetes outcomes, with a disproportionate negative effect in racial and ethnic minorities, and low-income families (18), future studies should include more diverse samples of teens with type 1 diabetes. For example, views and perceptions of importance of self-care in families with low (health) literacy skills may be different than in families with higher (health) literacy skills. Second, the current study spanned a time period of 18 months. Given how teen readiness for independent self-care is likely an evolving process that requires a sequential transfer of responsibilities for diabetes self-care tasks from parents to teens (9), future research may consider a longer study duration. This may enable the RISQ-T and RISQ-P to capture more nuance and change over time. Further, this research was performed just prior to the current time that has witnessed a greater penetration of advanced diabetes technology use into the adolescent population (19; 20). Thus, future research should examine teen readiness for independent self-care in the context of these advancements. Lastly, as this study was performed in a US population, future cross-national and cross-continental research is warranted to translate findings to different countries with different health care systems.

Despite these limitations, the current study may have important clinical implications. In the current era of person-reported outcomes (21; 22), the RISQ-T and RISQ-P may be ideally suited for implementation in clinical practice, capturing the evolution of teens' readiness for independent self-care over time, as an important precursor to transfer from pediatric to adult health care services. For example, implementation of yearly assessment into routine

diabetes care may help chart teens' progress toward more autonomous management and indicate those in need of greater support. Furthermore, this assessment may help evaluate the effects of transition preparation programs developed for teens on the verge of transfer to adult health care (e.g.,(19)). Moreover, our findings also reveal an opportunity for diabetes healthcare teams to provide additional review of and support for diabetes self-care behaviors during the adolescent years, as teens display less adherent self-care behaviors as they become older.

In conclusion, teen and parent perceived teen readiness for independent self-care shows predictive value for teen and parent perceived teen self-management but not glycemic outcomes over time. Future research is needed to design, implement, and evaluate interventions to increase readiness for independent self-care and self-care behaviors, with the ultimate goal of optimizing HbA1c in teens with type 1 diabetes.

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Novelty Statement

- The recognized challenges with transition from pediatric to adult health care likely stem from a lack of readiness for independent self-care during adolescence.
- In the current study we examined perceptions of readiness for independent self-care uniquely from teen and parent perspectives.
- Findings indicate that greater readiness for independent self-care related to greater self-care by the teen but not to better HbA1c.

Table 1.

Participant Characteristics (N=178)

	Youth
	Mean ± SD or n (%)
Age (years)	14.9±1.3
Sex (female)	85 (48)
Ethnicity (non-Hispanic white)	156 (88)
Insulin regimen (pump)	120 (67)
Parent Marital Status (married)	155 (87)
Parent Education (college degree or higher)	129 (72)
Family income (≥$100K)	102 (58)
Diabetes duration (years)	7.4 ± 3.7
BG monitoring frequency (times/day)	4.9 ± 2.0
HbA1c (%; mmol/mol)	8.5 ± 1.0; 69 ± 11

Table 2.

Measurements over time

	Baseline	6 months	12 months	18 months	*P*
RISQ **Teen** **Parent**	69.3 ± 11.7 58.7 ± 13.6	70.8 ± 11.2 60.1 ± 12.8	71.8 ± 10.5 61.3 ± 11.0	74.1 ± 10.3 62.6 ± 12.3	< 0.001 < 0.001
DMQ **Teen** **Parent**	71.5 ± 11.5 71.2 ± 13.8	69.5 ± 13.9 69.6 ± 14.0	68.3 ± 14.6 68.4 ± 13.1	67.3 ± 14.9 66.8 ± 13.4	< 0.001 < 0.001
HbA1c (%)	8.5 ± 1.0	8.7 ± 1.2	8.6 ± 1.2	8.6 ± 1.2	0.23

Values are M±SD; *P* value represents paired t-test between baseline score and 18 month score