

Youth and Parent Knowledge and Communication About Major Complications of Type 1 Diabetes

Associations with diabetes outcomes

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OBJECTIVE—Previously, we studied clinicians' and parents' perspectives about what, when, and how youth with type 1 diabetes (T1D) and parents should be taught about major complications (MC) of T1D. Results showed that this topic creates considerable anxiety among youth and parents, that there is a perceived need to tailor these experiences to each patient's circumstances, and that there is considerable variability in opinions about appropriate MC education. Prior studies did not measure youths' or parents' actual knowledge of complications, how they cope with that knowledge, or how these variables relate to T1D outcomes. The current study addresses these gaps.

RESEARCH DESIGN AND METHODS—This article reports a cross-sectional study of 151 8- to 18-year-old youths with T1D and their parents in which their knowledge of MC (nephropathy, retinopathy, neuropathy, and cardiovascular disease) was ascertained by structured interview. Family communication about MC was assessed using a questionnaire validated in this study. Regression analyses explored youth age, parent and youth MC knowledge, and positive family communication about MC as predictors of T1D outcomes (hemoglobin A_{1c}, treatment adherence, quality of life, and family conflict about T1D).

RESULTS—Parental MC knowledge was not associated with any T1D outcome; greater youth MC knowledge predicted better treatment adherence. More frequent optimistic family communication about MC was associated with more favorable status on all outcomes.

CONCLUSIONS—Optimistic family communication about MC, more so than MC knowledge, predicted favorable T1D outcomes. Longitudinal studies are needed to confirm these associations and to evaluate pertinent psychoeducational interventions.

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The issue of what, when, and how to teach parents and youth about the major complications (MC) of type 1 diabetes (T1D) is problematic. Although avoidance of MC is central to T1D management, parent or child exposure to too much MC information too soon could exert negative psychological effects (anxiety, depression) that might impede effective T1D care. Yet, such information is readily available via the Internet and publications. Refraining from teaching about this topic altogether could undermine patients' and parents' trust in their health care providers and risk exposing

youth and parents to incorrect or outdated information. We have conducted several studies of this dilemma, including a focus group study of parents about their experiences and perspectives about how they and their children learned about MC (1) and online quantitative surveys of pediatric diabetes clinicians (2) and parents (3) regarding these issues. From these studies, participants expressed consistent opinions that information about MC is quite threatening emotionally (1–3), that teaching about MC should be deferred until several months after the diagnosis (1–3), that the level of detail provided

should be tailored to the child's developmental and emotional maturity (1–3), and that parents should have input into what, how, and when this is presented to their children (1–3). Despite these consistent findings, the three studies also revealed substantial variability in opinions regarding specifics such as the earliest ages (1–3) or time since diagnosis (1–3) at which children should first be exposed to this information, as well as in the level of detail that should be shared. Additionally, this work identified factors that influence variability in the propensity of health care professionals to disclose MC information to youth and parents (4,5), explored associations between youth and parent coping with MC information (6), validated several measures, including a self-report questionnaire derived from a previously validated structured interview for the measurement of T1D treatment adherence (7), a structured interview to assess youth and parent MC knowledge (8,9), and a self-report questionnaire to assess family communication about MC (10). To our knowledge, these are the only studies of youth and parent knowledge of T1D complications or their coping with that information.

These initial studies provided important perspectives of appropriate education about MC but did not evaluate how youth or parent knowledge about MC is associated with behavioral, psychological, or metabolic T1D outcomes. Accurate MC knowledge could motivate meticulous self-care by giving youth and parents an important long-term goal. More accurate MC knowledge could induce some families to talk about avoidance of complications in a positive and optimistic manner, affirming careful self-management as a mechanism for reducing MC risks. Conversely, more knowledge about MC could also be perceived as threatening and lead some youth and parents to despair about the value of careful T1D management. Some parents and youth could be so overwhelmed by the risks of MC that they could view meticulous self-care as futile. The

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current study sought to clarify whether either of these interpretations is correct and to characterize cross-sectional relationships among MC knowledge, family communication about MC and selected T1D outcomes. The study addressed these specific questions: 1) Is knowledge of MC significantly associated with metabolic (HbA_{1c}), behavioral (diabetes self-management behaviors), and psychological (diabetes-related family conflict; quality of life) outcomes of T1D management? 2) Is greater knowledge of MC among parents and youth associated with the frequency of optimistic family interactions about complications? and 3) Are more frequent optimistic family interactions about MC associated with better metabolic (HbA_{1c}), behavioral (diabetes self-management), and psychological (diabetes-related family conflict; quality of life) T1D outcomes?

RESEARCH DESIGN AND METHODS

Participants and setting

Enrollment criteria were designed to enlist a diverse sample of youth with T1D and their parents/caregivers at two urban pediatric diabetes centers in the Southeastern U.S. Youth must have had T1D for ≥1 year and be 8- to <18 years old. Parents/caregivers (85% biological mothers) were expected to be involved in the child’s daily T1D care. All participants were required to have sufficient fluency in English to permit completion of the study measures. Parents/caregivers received an informational letter about the study, followed by telephone or direct contact with a research assistant. Once their eligibility was verified, interested participants then signed institutionally approved parental permission or assent forms before any research data were collected. Of the 378 families who were sent the informational letter, a total of 234 were contacted by a research assistant, and 26 of them were found to be ineligible. Of the 352 who were sent the letter and known to be eligible, 43% enrolled. Of the 208 who were contacted directly and known to be eligible, 73% enrolled.

Participants were 151 youth with T1D for ≥1 year and a parent or other legal caregiver of each. Demographic characteristics (mean ± SD) of the participating youth were as follows: age, 13.9 ± 2.3 years; diabetes duration, 5.5 ± 3.4 years; and HbA_{1c}, 8.7 ± 1.8%. Participants were diverse in terms of youth, sex (49.7% female), ethnicity

(89% non-Hispanic), race (77% Caucasian, 13% African American, 10% other), family composition (82% two parent and 18% one parent), and annual household income (73% between \$32,875 and \$126,500). Mean ± SD parental education was 14.0 ± 1.2 years. Most youths (89%) were on either insulin pump or multiple daily injection regimens utilizing basal-bolus insulin dosing principles and carbohydrate counting for dietary management. The others were on conventional fixed dose insulin regimens and were not using carbohydrate counting. These characteristics are similar to those of participants in recent, similar studies in this setting.

Procedures

Participants completed study participation during one research visit. Data on HbA_{1c} and duration of T1D were extracted from children’s medical records. If a child couldn’t read the questionnaires, a research assistant read the items to the child and recorded the child’s responses. Table 1 presents descriptive statistics, possible range of scores, and α-coefficients (internal reliability) calculated from the results of the present sample for each measure. Psychometric properties of all measures that entered the statistical analyses were satisfactory.

Measures

General information form. Parents provided relevant demographic information, medical history, and occupational and educational information.

Glycosylated hemoglobin (HbA_{1c}). HbA_{1c} was measured at both sites using the DCA-2000+ glycohemoglobin analyzer (Bayer Diabetes Care, Tarrytown, NY). The reference range is 4.0–6.0%, and coefficient of variation is 2.2%. The most

recently obtained result was obtained from each child’s medical record. In most cases these were obtained on the day of the study visit.

Knowledge about diabetes and future health (KADFH). This structured interview was constructed by the authors (8,9), with guidance from several pediatric endocrinologists and diabetes educators. The intent was to measure youth’s and parent’s knowledge of major T1D complications without exposing them to any information about this sensitive topic that they did not already have. Parents and youth were interviewed separately, and the interviews were audio-recorded. Open-ended basic questions about T1D and long-term health, if answered correctly, were followed by open-ended questions about organ systems that might be affected adversely in people with T1D. If both initial open-ended questions were answered incorrectly, the interview was stopped. In response to open-ended questions about specific organ systems that might be affected by diabetes long term, the interview was stopped if the participant did not name the heart, eyes, kidneys, or nerves. If the respondent correctly identified any of these organs, these more detailed questions were asked about each organ system that was identified: “What exactly can go wrong with this organ?”; “What causes this to happen?”; “Can this problem be prevented?”; “Once it has started, does this problem ever go away?”; “What tests do doctors use to see if a person with diabetes has this problem?”; and “What treatments are there for this problem?” Organ-specific scoring criteria (0, incorrect or did not answer; 1, partially correct response; and 2, correct response with at least one pertinent detail) were applied to assign each participant a total MC knowledge score. Higher

Table 1—Descriptive statistics and α-coefficients for the study questionnaires

Measure	Mean	SD	Possible range	α-Coefficient
KADFH				
Parent	32.1	11.5	0–65	0.82
Youth	17.8	11.8	0–65	0.89
FCDFH composite	82.2	10.5	30–120	0.83
DSMP-SR composite	55.0	10.9	0–86	0.81
DFCS				
Parent	28.1	7.1	19–57	0.90
Youth	28.9	8.0	19–57	0.91
PedsQL				
Parent	37.5	16.9	0–112	0.89
Youth	33.0	17.5	0–112	0.89

scores (possible range, 0 to 65) indicated more accurate and detailed MC knowledge. Scoring of questionable responses was achieved by consensus among several research team members. Mean \pm SD total scores were 32.1 ± 11.5 for parents (49% of maximum score) and 17.8 ± 11.8 for youth (27% of maximum score), indicating generally low levels of MC knowledge. Internal consistency (α -coefficient) was 0.89 for youth and 0.82 for parents. Total scores correlated 0.24 with youth age ($P < 0.01$), and parent-child scores correlated 0.34 ($P < 0.01$).

Family communication about diabetes and future health (FCDFH). This 30-item scale, constructed by the authors (10), measures the extent to which family communication about MC is frequent, optimistic, and positive. The first 12 items consist of statements describing family communication, which the respondent rates on a four-point scale from "Not at all like my family" (example: "We talk about avoiding future health problems through good daily diabetes habits"), followed by 18 quotes potentially made by youth or parents, rated on the same response scale (example: "You can be whatever you want to be if you take good care of yourself"). Higher scores reflect more positive and constructive family communication about MC. Because parent and youth total scores correlated quite strongly (Pearson $r = 0.57$; $P < 0.0001$), a composite score was derived, consisting of the mean of the parent and youth scores on the measure. Internal consistency (α -coefficient) for the composite score was 0.83. The composite score entered all analyses described below.

Diabetes self-management profile–self-report form (DSMP-SR). This is a 24-item self-report form (7) of a previously validated structured interview (11,12) that quantifies diabetes self-management behaviors. Separate forms were constructed for patients on flexible (insulin pump or basal-bolus insulin injection regimens with use of carbohydrate counting) or conventional (fixed dose insulin injection regimens without use of carbohydrate counting). Higher scores are indicative of more meticulous T1D management. The scale was completed by parents and youth who were at least 11 years old. Because parent and youth scores correlated strongly ($r = 0.64$; $P < 0.0001$), a composite score, consisting of the mean of the parent and youth scores on the measure, entered all reported analyses.

PedsQL diabetes module (PedsQL). This 28-item scale measures youths' diabetes-related quality of life, with higher scores indicating better quality of life (13). Parent-youth scores correlated 0.40 ($P < 0.001$).

Diabetes family conflict scale–revised (DFCS). This 19-item measure of T1D-related family conflict was recently updated from an earlier version (14). Higher scores indicate more family conflict about T1D. Youth-parent scores correlated 0.49 ($P < 0.0001$).

Statistical analyses

SPSS Version 19.0 was used for all analyses (15). Assumptions were verified before conducting the analyses described below. Descriptive and correlation analyses preceded planning of multivariate modeling. Hierarchical regression models were then constructed for each T1D outcome variable (HbA_{1c}, DSMP-SR composite, and youth and parent scores on the PedsQL and DFCS). Predictor variables were entered in blocks as follows: Block 1: youth age, because of its significant correlations with many of the outcomes in similar studies; Block 2: youth and parent scores for MC knowledge (KADFH); Block 3: composite youth and parent scores for MC communication (FCDFH); and Block 4: two-way interaction terms for the measures entered in blocks 2 and 3. All tests were two-tailed at the $P = 0.05$ level of significance.

RESULTS

Descriptive statistics

Table 1 presents descriptive statistics, possible ranges, and α -coefficients for each questionnaire. Of note, mean parental and youth KADFH scores suggest that both sets of participants demonstrated limited knowledge of the major T1D complications. Mean composite scores (82.3 ± 12.1) on the FCDFH measures indicated moderate self-reported frequency of positive family communication about MC compared with the maximum score of 120. Mean scores for the T1D outcome measures for this sample were similar to those observed for prior research participants in this setting. All questionnaires had acceptable internal consistency with all α -coefficients > 0.80 .

Correlations between predictor and outcome variables

Youth age was associated significantly with scores on both the KADFH ($r = 0.24$;

$P < 0.01$) and FCDFH (-0.31 ; $P < 0.001$) and youth age has been associated elsewhere with several T1D outcomes of interest, such as HbA_{1c}, DSMP-SR, and DFCS (16). No other demographic variables were associated with any of the predictor or outcome variables, and so youth age was the only demographic variable entered into the final multivariate models.

As shown in Table 2, correlation analyses were completed to explore associations among the predictor variables and outcome variables. Parent KADFH scores did not correlate significantly with any of the outcome measures (range of r from -0.06 to 0.08 ; $P > 0.10$ for all). Youth KADFH scores correlated significantly with the DSMP-SR composite score ($r = 0.26$; $P < 0.001$) and with the FCDFH composite score ($r = 0.37$; $P < 0.001$). The FCDFH composite score correlated significantly with HbA_{1c} (-0.42 ; $P < 0.0001$), DSMP-SR (0.64 ; $P < 0.0001$), DFCS parent (-0.54 ; $P < 0.0001$), DFCS youth (-0.30 ; $P < 0.001$), PedsQL parent (0.43 ; $P < 0.001$), and PedsQL youth (0.33 ; $P < 0.001$).

Hierarchical regression analysis

For all regression models that were tested, the authors verified that the assumptions for these analyses had been met and that none of the entered variables demonstrated significant deviation from normality or linearity. Collinearity diagnostics were performed and revealed no evidence of significant multicollinearity that might obscure interpretation of the regression analyses presented below.

Results for the final regression models, as summarized in Table 3, showed that youth age accounted for unique variance in DSMP-SR (adjusted $R^2 = 0.087$; standardized $\beta = -0.175$) but none of the other outcomes. Youth KADFH scores and parent KADFH scores did not account for a significant proportion of unique variance in any of the T1D outcomes. However, the composite score on the FCDFH accounted for additional unique variance (adjusted R^2 change) in HbA_{1c} (17.0%; standardized $\beta = -0.445$), DSMP-SR (32.9%; standardized $\beta = 0.605$), DFCS parent (27.2%; standardized $\beta = -0.551$), DFCS youth, PedsQL parent, and PedsQL youth (9.4%; standardized $\beta = 3.75$). None of the two-way interaction terms that were entered accounted for a significant proportion of unique variance in any of these analyses.

Table 2—Intercorrelations between predictor and outcome variables

	1	2	3	4	5	6	7	8	9
KADFH									
Parent	—								
Youth	0.24*	—							
FCDFH composite	−0.03	0.33**	—						
HbA _{1c}	0.08	0.05	−0.42***	—					
DSMP-SR composite	−0.06	0.26**	0.64***	0.45***	—				
PedsQL									
Parent	0.06	0.02	0.43***	0.43***	0.35**	—			
Youth	−0.02	−0.02	0.33**	0.43***	0.36**	0.40***	—		
DFCS									
Parent	−0.05	0.13	−0.54***	0.44***	−0.44***	−0.60***	0.29**	—	
Youth	−0.07	−0.09	−0.30**	0.30**	−0.13	−0.33**	−0.39***	0.49***	—

* $P < 0.05$; ** $P < 0.001$; *** $P < 0.0001$; all others are nonsignificant.

CONCLUSIONS—We sought to expand previous qualitative and Internet survey research on youth and parent knowledge of major T1D complications and about how parents, youth, and health professionals perceive the process of acquiring this knowledge and its psychosocial effects. This study advances that research by obtaining objective indexes of youth and parent MC knowledge concurrently with validated measures of the extent of optimistic family communication about MC, along with several pertinent outcomes of T1D care.

Both parents and youth scored quite low on a structured interview (KADFH) that was carefully designed to reveal their levels of MC knowledge without exposing them to information that they did not already possess. Mean scores on this measure were equivalent to 49% of maximum for parents and 27% of maximum for youth. Correlation analysis showed that youth KADFH scores correlated significantly with youth age, the DSMP-SR composite score, and the FCDFH family composite score. Neither youth nor parent KADFH scores correlated significantly with HbA_{1c}, DFCS, or PedsQL scores.

Hierarchical multiple regression analyses showed that youth age accounted for unique variance in DSMP-SR scores but not in any of the other outcomes. Older youth demonstrated poorer adherence, consistent with much prior research (16). With age controlled, neither youth nor parent KADFH scores accounted for unique variance in any T1D outcome. Composite FCDFH scores accounted for substantial unique variance in all of the T1D outcomes, ranging from 9.4 to 32.9% of additional unique variance

beyond the contributions of youth age and youth and parent KADFH scores.

Despite marginal MC knowledge among youth with T1D and their parents, families who reported more frequent positive and optimistic family communication

about MC also tended to realize more favorable status in terms of HbA_{1c}, treatment adherence, diabetes-related family conflict, and quality of life. Because these associations were independent of youth or parent MC knowledge, it appears that

Table 3—Results of hierarchical regression analyses

Outcome measure	Adjusted R ²	Standardized β	F for R ² change	P value
HbA _{1c}				
Youth age	0.006	0.101	1.94	NS
KADFH	−0.004	0.074 (parent), −0.170 (youth)	0.24	NS
FCDFH composite	0.170	−0.445	30.74	0.0001
DSMP-SR composite				
Youth age	0.108	−0.246	18.48	0.0001
KADFH	0.099	−0.048 (parent), −0.073 (youth)	0.34	NS
FCDFH composite	0.439	0.615	87.01	0.0001
DFCS parent				
Youth age	0.015	0.003	3.14	NS
KADFH	0.009	−0.054 (parent), −0.083 (youth)	0.60	NS
FCDFH composite	0.283	−0.552	54.41	0.0001
DFCS youth				
Youth age	−0.005	−0.021	0.23	NS
KADFH	−0.009	−0.071 (parent), −0.154 (youth)	0.75	NS
FCDFH composite	0.102	−0.358	18.36	0.0001
PedsQL parent				
Youth age	−0.005	0.018	0.28	NS
KADFH	−0.015	0.083 (parent), −0.167 (youth)	0.28	NS
FCDFH composite	0.183	−0.474	35.48	0.0001
PedsQL youth				
Youth age	−0.004	0.071	0.38	NS
KADFH	−0.014	−0.007 −0.182	0.31	NS
FCDFH composite	0.108	−0.376	20.45	0.0001

NS, nonsignificant.

positive and optimistic family communication about MC may be associated with benefits even for families who possess only very fundamental MC knowledge. Knowing that T1D carries risks of serious long-term health problems and that these risks can be attenuated through effective glycemic control may be sufficient MC knowledge. Articulation of detailed information regarding the nature, causes, detection, prevention, and treatment of the major T1D complications does not appear to be a prerequisite to families addressing these threats constructively.

Given the cross-sectional nature of this study, it is possible that effective T1D management generates positive family communication about MC, rather than there being a causal relationship in the opposite direction. Hence, it would be premature, on the basis of a single cross-sectional study, to encourage widespread promotion of family communication about MC. But, when families do communicate about this sensitive topic, it is important that their interactions emphasize constructive problem solving and optimism about how effective daily management of T1D can reduce MC risks. Expressions of threats, guilt, scare tactics, belittlement, or other types of negative communication about MC are unlikely to be associated with favorable T1D outcomes. Further longitudinal study of these family processes would be valuable and could point to fruitful targets for intervention.

Another important finding from this study is that knowledge of MC did not appear to be associated with adverse metabolic, behavioral, or psychological outcomes. Learning more about major complications of T1D does not appear to place youth or their parents at higher risk of psychological or behavioral problems that are severe enough to impede family management of diabetes. However, the study did not include measurement of depression or anxiety disorders and so it remains possible that MC knowledge could be associated significantly with these disorders that are quite common in youth with T1D and their parents (16). It remains possible that both positive and negative psychological reactions to MC knowledge could occur, yet be undetectable when aggregated results are analyzed.

The cross-sectional nature of the current study impedes drawing any conclusions regarding the direction of causality, if any, that yielded the identified associations. Longitudinal analysis of the same associations reported in this study could begin to clarify any causal relationships and suggest appropriate clinical and educational interventions. The current study extends knowledge regarding how families' MC knowledge and communication patterns might affect how they cope with the threatening information that accompanies MC risks. Additional longitudinal research on these questions could perhaps lead to the development and validation of an optimal strategy for education of families about this sensitive topic and for guiding them in coping with it in a constructive manner.

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No potential conflicts of interest relevant to this article were reported.

T.W. conceived the study design, directed the study implementation, analyzed data, and directed manuscript preparation. A.L., H.A., and L.M.B. participated in the design and implementation of the study and participated in manuscript preparation.

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