Published in final edited form as:

J Pediatr Health Care. 2014 ; 28(5): 376–385. doi:10.1016/j.pedhc.2013.09.002.

Using Qualitative Methods to Evaluate a Family Behavioral Intervention for Type 1 Diabetes

Linda Jones Herbert, PhD¹, Rachel Sweenie, BA¹, Katherine Patterson Kelly, RN, PhD¹, Clarissa Holmes, PhD², and Randi Streisand, PhD¹

¹Center for Translational Science Children's National Medical Center 111 Michigan Ave., NW Washington, DC 20010

²Department of Psychology Virginia Commonwealth University 1111 W Broad St. Richmond, VA 23220

Abstract

Introduction—The objectives of this study were to qualitatively evaluate a dyadic adolescent-parent type 1 diabetes (T1D) program developed to prevent deterioration in diabetes care among adolescents with T1D and provide recommendations for program refinement.

Method—Thirteen adolescent-parent dyads who participated in the larger RCT, the TeamWork Project, were interviewed regarding their perceptions of their participation in the program and current T1D challenges. Interviews were transcribed and coded to establish broad themes.

Results—Adolescents and parents thought the TeamWork Project sessions were helpful and taught them new information. Five themes catalog findings from the qualitative interviews: TeamWork content, TeamWork structure, transition of responsibility, current and future challenges, and future intervention considerations.

Discussion—Addressing T1D challenges as a parent-adolescent dyad via a behavioral clinic program is helpful to families during adolescence. Findings highlight the utility of qualitative evaluation to tailor interventions for the unique challenges related to pediatric chronic illness.

Keywords

qualitative; type 1 diabetes; adolescents; behavioral intervention

Introduction

Type 1 diabetes (T1D) is a common pediatric chronic illness that requires adherence to a complex care regimen involving daily blood glucose monitoring, insulin administration, and

© 2013 National Association of Pediatric Nurse Associates and Practitioners. Published by Mosby, Inc. All rights reserved.
lherbert@cnmc.org, rstreis@cnmc.org, kakelly@cnmc.org, cholmes@richmond.edu, rsweenie88@gmail.com

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

The authors have no disclosures to report.

regulation of nutrition and physical activity (American Diabetes Association, 2013). Deterioration in adherence and glycemic control is common during adolescence as responsibilities for diabetes care tasks begin to shift from parent to child (Greco et al., 1990; Johnson et al., 1992); adolescents' strive for more independence while at the same time engaging in more risk-taking behavior, which may result in decreased adherence behaviors such as fewer blood glucose (BG checks), inconsistent carbohydrate counting, and missed insulin doses. A dynamic array of parent and child factors can impact disease management. For example, maternal involvement in adolescents' T1D care that is collaborative in nature, rather than controlling, has been shown to relate to better adherence and glycemic control (Wiebe et al., 2005), and adolescents who display positive qualities, such as friendliness and honesty, perceive greater family cohesion and exhibit better disease management (Mackey et al., 2011).

Behavioral interventions that incorporate multiple family members and address communication, problem-solving, and coping strategies have the potential to reduce adolescent and parent difficulties related to T1D management and decrease the likelihood of declines in T1D management during adolescence (Hampson et al., 2000). Several such interventions for adolescents with T1D have demonstrated partial success. In one, adolescents participated in a coping skills training program, after which they exhibited short-term improvements in quality of life and glycemic control (Grey et al., 1998). In another clinic-based parent-adolescent program, parents randomized to the intervention group demonstrated less deterioration in involvement during insulin administration and blood glucose monitoring and adolescents exhibited improved glycemic control at one year follow up (Anderson, Brackett, Ho, & Laffel, 1999). Finally, using behavioral family systems therapy, adolescents have demonstrated long-term improvements in communication, family interaction, and problem solving (Wysocki et al., 2008). Continued development and evaluation of behavioral interventions such as these may delineate additional therapeutic elements that maintain or improve glycemic control during adolescence.

In addition to conducting rigorous randomized clinical trials (RCT) to determine the efficacy of such interventions, qualitative research methods can be used as an adjunct, and, in particular, can aid program development, evaluation, and refinement. Qualitative studies are used widely among pediatric populations prior to intervention development to identify the challenging aspects of disease management that might benefit from intervention, clarify target behaviors and outcomes, and anticipate barriers to intervention delivery and acceptance (Sandelowski, 1996). Qualitative methods have been used to assess the unique challenges and needs of adolescents with T1D transitioning to adult medical facilities (Price et al., 2011), outline the developmental pathways of disease cognitions and behavior among parents of children with food allergy (DunnGalvin, Gaffney, & Hourihane, 2009), and identify the stressors and self-management responsibilities of minority children and adolescents with asthma (Martin, Beebe, Lopez, & Faux, 2010). Researchers used results from individual interviews and focus groups to make informed decisions when developing intervention protocols and delivery methods.

Qualitative methodology is also useful after an intervention has been implemented to evaluate process variables such as intervention delivery, identify populations that most

benefit from the intervention, and incorporate successful modifications that maximize intervention efficacy (Sandelowski, 1996). These methods have been used frequently among a variety of pediatric populations and provide unique insight regarding the intervention experience: Monaghan and colleagues (2011) conducted detailed qualitative interviews with parents of young children with T1D who participated in a telephone-based support intervention, which elicited parents' desire for more educational and supportive intervention components closer to the time of diagnosis (Monaghan, Sanders, Kelly, Cogen, & Streisand, 2011). Hartmann and colleagues (2007) completed phone interviews with families who participated in an asthma intervention website and found that parents believed the program changed their attitude about their interactions with their child's physician and prompted them to be more active participants in clinic appointments (Hartmann et al., 2007). Similarly, Buelow (2007) used an iterative model during which parents of children with epilepsy were interviewed following each stage of intervention development, providing crucial insight regarding the length of time needed for parent education and the importance of establishing partnerships with the health care team (Buelow, 2007). Based on their findings, the researchers of these three studies believed they were able to improve future interventions and employ a broader context when interpreting quantitative data.

Collectively these studies suggest that the use of qualitative methods among a variety of pediatric populations is an essential method for developing and refining behavioral interventions. The goal of the present study was to qualitatively evaluate and refine a coping skills prevention program developed to prevent deterioration in glycemic control among adolescents with T1D. In-depth interviews with a subset of adolescents and their parents were utilized to 1) evaluate participants' experiences with and perceptions of the acceptability and usefulness of the coping skills and education sessions and 2) identify issues that adolescents and parents would like addressed in a future program to be developed for older adolescents. Results of the qualitative analysis were synthesized with quantitative data to provide clear feedback regarding the coping skills and education sessions and recommendations for future interventions.

Methods

Participants

Participants in the present study were recruited from a larger pool of participants who had completed the TeamWork Project, a RCT designed to prevent deterioration of glycemic control among early adolescents with T1D. As part of the larger RCT, 226 adolescents, ages 11 to 14 years, and their primary caregivers, were recruited from two Mid-Atlantic children's hospitals and randomized to either the coping skills or education group and subsequently met with a study team counselor at four consecutive regularly scheduled diabetes clinic visits. Coping skills session topics included communication and diabetes management, problem solving to improve blood glucose management, healthy food choices and avoiding arguments, and how attitudes affect behaviors and how these relate to physical activity. Each session started with an overview of the skill and was followed by a discussion about what was typical for the family and how they could use the skill in daily life. See Mackey et al. (2011) for detailed information regarding the TeamWork protocol.

A purposive sample of twenty-one families were identified (10 coping skills; 11 education) based on adolescents' sex, age, change in HbA1c from baseline assessment to first follow up assessment (i.e., increased > 0.5%, decreased > 0.5%, or did not change), and length of time since program completion. This selective, intentional qualitative research sampling method was designed to ensure a range of perspectives (Sandelowski, 2000). Of these, fourteen families (67%) agreed to participate; the other 7 families were unable to be reached by phone despite several messages from the research team. Of the families who agreed to participate, 13 adolescents-parent dyads (93%) completed interviews. One parent asked to reschedule at a designated interview time and was subsequently unable to be reached by phone. At the time of the interview, adolescents had a mean age of 15.71 years ($SD = 1.10$, $Range = 14-17$) and 61.5% were female; mean length of time since TeamWork session completion was 2.07 years ($SD = .51$, $Range = 1.25-3.09$). Of the interview participants, HbA1c levels for 5 adolescents increased from baseline to the first follow up assessment (M change = +1.1%, $Range = +0.6\%$ to +1.7%), decreased for 4 adolescents (M change = -1.5%, $Range = -1.3\%$ to -1.8%), and remained stable for 4 adolescents (M change = -0.1%, $Range = -0.4\%$ to +0.3%). Primary caregivers included eleven mothers, one father, and one grandmother. The sample was primarily Caucasian (85%), which is higher than the percentage of Caucasians in the overarching study (69%). Seven dyads had been randomized to the coping skills group; six dyads were from the education group.

Procedures

Families were mailed recruitment letters regarding the study over a three-month period. Approximately two weeks after receipt of the letter, a study team member contacted families by phone to assess interest and eligibility. Families who agreed to participate were then scheduled to complete a phone interview at their convenience. Separate adolescent and parent semi-structured interviews were led by two trained study team members and lasted approximately 28 minutes for adolescents ($SD = 8.55$, $Range = 20-55$) and 37 minutes for parents ($SD = 9.22$, $Range = 25-55$). Interviews were split into two parts: the first half focused on participants' experiences in the four in clinic sessions and the second half included questions about what participants would like to be addressed in a similar program for older adolescents. Example prompts included, "Tell me about your experiences in the four TeamWork sessions" and "What parts of diabetes would you like to discuss in a program like TeamWork now?" Families were compensated \$50 for their participation. In addition to the qualitative interviews, dyads had completed a satisfaction survey after completion of the four TeamWork program sessions.

Data Analysis

We applied conventional content analysis (Hsieh & Shannon, 2005) to the verbatim transcripts of the audio recorded interviews and detailed field notes taken during the interviews. Using inductive approaches common to qualitative content analysis, the textual data were classified into codes and themes to organize and classify participants' descriptions of their study experiences as follows. The first author read three initial transcripts several times to obtain a global understanding of the participants' overarching ideas and feelings. Phrases that portrayed key thoughts or concepts were highlighted and constituted the units of analysis. These text units were then coded using labels that reflected the key thought or

concept. The second author then independently coded a 4th transcript using the same process. After this all codes were discussed and jointly defined by the two authors. The senior author then reviewed and confirmed code definitions and assignment. Any coding discrepancies were resolved by consensus agreement. The remaining 6 transcribed interviews were then coded with no additional codes added. In 3 of the 13 interviews, a recorder malfunction occurred. Field notes for these interviews were compared to other interview transcripts to determine adequacy of these notes for analysis. Fortunately, the field notes were detailed enough to code and were, therefore, included in the final analysis. Codes that represented broader conceptual ideas were grouped into themes to facilitate reporting final results. We used NVivo 8.0 software to manage the qualitative data. Satisfaction survey data were available from 12 of the 13 dyads and were analyzed using frequency statistics via SPSS 20.0 software.

Results

Participant Satisfaction Survey

Most adolescents (50%) and parents (58%) thought the TeamWork Project sessions were “pretty helpful.” Similarly, most adolescents (58%) and parents (50%) reported that they learned a “decent amount” from the sessions despite having finished on average 2 years previously; coping skills participants (75%) believed that they learned more new information than education group participants (33%). With respect to the coping skills sessions, the majority of adolescents and parents said that the communication session (67% of adolescents, 83% of parents), problem solving session (83% of adolescents, 83% of parents), avoiding arguments session (67% of adolescents, 83% of parents), and attitude/behavior change session (67% of adolescents, 83% of parents) were “pretty helpful” or “very helpful.” Half of adolescents and parents in the coping skills group named the avoiding arguments session as their favorite session.

Interview Data

Two overarching TeamWork program themes emerged: ‘TeamWork content,’ and ‘TeamWork structure.’ Three T1D management-related themes were also identified: ‘transition of responsibility,’ ‘current and future challenges,’ and ‘future intervention considerations.’ Codes within each theme were also identified. Definitions and examples for each code are presented in Table 1.

TeamWork content

Reinforcement: Participants in both groups noted TeamWork supported their use of current T1D skills and reinforced previous T1D education. Noted one mother, “[The program] reaffirmed what I was doing; that I was trying to do [T1D management] right.”

Communication and problem solving: All parents and most adolescents in the coping skills group believed that TeamWork helped their family discuss T1D challenges and concerns more effectively and encouraged the use of effective problem solving strategies. According to one mother, she and her daughter now “have that rapport and the ability to discuss [T1D].” Many participants believed communication was an essential component of

TeamWork because it affects so many other aspects of T1D management and helped them communicate with other family members.

New perspectives and skills: TeamWork helped coping group participants understand their other family members' T1D perspectives and taught them concrete skills they could apply at home. Parents, in particular, stated that it was easier to manage their T1D-related stress if they accounted for their adolescent's opinions and views about T1D and were given T1D-related information directly from the counselor. Noted one father, "As a parent, you worry so much about the highs, the lows, but the kids- they don't think about that. It kind of helped keep it in perspective so that we don't get into arguments." Similarly, another parent stated that, "You felt like when you left, you had something concrete you could do."

Program was beneficial: The majority of participants in both the coping skills and education groups indicated that they liked TeamWork and thought it was helpful. In particular, participants liked the materials, such as study magnets and handouts, and the concrete skills they learned which could apply to other situations and caregivers. According to one adolescent, "I found that talking through stuff, especially with my mom through this program, has helped me to handle situations with my dad also." Similarly, a mother who had two children with T1D reported that some of the topics "were not at all relevant to my daughter [who was in the study], but were very applicable to my son [who was not in the study]."

Return to old habits: Despite the benefits participants attributed to TeamWork, some coping skills group participants acknowledged that it is easy to forget new T1D skills and strategies over time, and therefore, it is difficult to enact long-term behavior change. One mother succinctly said, "It's easy to hear it and even to gain from it, but I think it's easy to slip back into old patterns and forget."

TeamWork structure

Session structure and timing: Most participants in both groups enjoyed the structure and timing of TeamWork sessions, including their co-occurrence with regularly scheduled diabetes clinic visits, because it was convenient and gave them something to do while waiting to see their physician. However, some participants disagreed and thought the co-occurrence made the appointment too long. With respect to the length of time between TeamWork sessions (3-4 months), participants had varying opinions. One mother stated, "You want to give time to kind of mull over and work on those issues in that particular session" but another parent thought that monthly sessions would be ideal. Some participants also wanted more than 4 sessions. Finally, most parents liked attending sessions with their adolescent; however, not all adolescents wanted their parent in the session with them. One adolescent noted, "I would have talked more if my dad wasn't in the room," while another indicated that "it was the same as if [my mom] wasn't there. I mean, she knows everything I do."

Varying T1D program needs: Both coping skills and education group participants noted that anyone can benefit from TeamWork, but specific youth may benefit the most,

depending on age, length of diagnosis, and glycemic control. Early adolescence was frequently cited as the most appropriate target age for TeamWork because “eighth grade, going into high school, was when you start becoming more independent” and is when more T1D problems may arise and adolescents become “tired of dealing with this.” Coping skills group participants were conflicted about whether or not TeamWork would be appropriate immediately after T1D diagnosis: some thought it would help orient patients to T1D whereas others thought it may be too overwhelming “when you're just trying to adapt to the very concrete carb counting, prescription managing kind of stuff.” In contrast, most education group participants felt “I would have loved to have those [sessions] when we were first diagnosed,” and one adolescent noted, “The topics came to us kind of late because I had already been diagnosed since I was six.” Participants in both groups also thought TeamWork could apply to patients of varying glycemic control. One adolescent stated, “If they're already doing a good job, then maybe they can just have new ideas on different things to try and make it better. But a person managing it poorly--then they need to know [these skills].”

Transition of T1D care

Allocation of T1D care responsibility: The majority of participants reported that adolescents were primarily responsible for T1D care, including blood glucose monitoring, insulin injections, and carbohydrate counting. Participants approximated that the shift in T1D care occurred around the beginning of high school. Families reported that adolescents gain confidence as they get older, are away from home more frequently, and parents trust them more. Parents also wanted to prepare their adolescents for independent living; as one mother stated, “He does go off to college real soon, so he's gotta learn to do it all on his own.” However, nearly all participants reported that parents were still involved in decision-making and monitoring of day-to-day T1D care by checking in with adolescents, attending clinic appointments, scheduling appointments, picking up prescriptions, and assisting with sick day management. Many participants indicated that parents are “managing the big, big picture” or providing “emotional support.” One parent also noted that if her adolescent was managing T1D poorly, she would take control of T1D management for a period of time. Participants reported that parents and adolescents work together for many aspects of T1D care as well, including insulin administration, basal rate/bolus adjustments, food choices, supply management, and pump site changes. One parent said that she and her daughter “constantly talk” about T1D and an adolescent indicated that, “If we need to adjust the insulin, we figure that out together.” Together, these data indicate that adolescents have greater responsibility for their daily T1D care, but that parents continued to be involved, suggesting that supporting constructive communication between parents and adolescents is an important intervention component for this population.

Current and future challenges—The majority of participants indicated that there were multiple challenges that complicate T1D management that should be addressed in an intervention for older adolescents. Stressors included physical activity, nutrition, BG management, stress, school, social support, driving, and post-high school plans. See Table 1 for additional details and examples of these sub-categories.

Future intervention considerations—Participants provided their thoughts about additional components that could be included in future interventions as well. Some noted that reeducation about previously learned T1D skills and T1D complications were significant topics to discuss with adolescents as they got older because “you definitely go through challenges in high school, and sometimes you forget... the little things.” Participants specifically mentioned a desire to learn more about the biological mechanisms of T1D, insulin regimen options, BG management, nutrition, travel, physical activity, seizures, T1D disclosure, and sexual complications. Some parents believed that regular check-ins with psychology are important and beneficial. Participants also believed that a variety of types of T1D-related technology could also be useful, such as websites, text messaging, phone applications, and social media, because they can provide T1D information, management assistance, social support, and “would help keep everything at [our] fingertips.”

Discussion

Qualitative methods are useful to evaluate the content and delivery of behavioral interventions. Parent and adolescent interviews effectively assessed participants’ experiences with and perceptions of the acceptability and usefulness of the TeamWork Project. Satisfaction survey data identified intervention components felt to be most useful to participants and interview data provided rich details about how the program was beneficial. Qualitative data also suggested that participants who received training in communication and problem solving skills perceived additional benefits from the program and incorporated these skills into their everyday activities post-intervention.

With respect to program content, participant feedback reinforced changes previously described in the literature that occur during adolescence when T1D responsibility shifts from parents to adolescents. As adolescents get older, they begin renegotiating boundaries and relationships, and decrease reliance on parents (Cincotta, 2008). This transition can be difficult to navigate and may introduce new T1D-related situations, such as independent T1D management away from home and a desire for increased privacy. Effective communication and problem solving with parents, peers, and other important figures in an adolescent’s life may ease the transition to independent T1D care and potentially prevent declines in T1D regimen adherence and/or glycemic control that often occur during adolescence (Johnson et al., 1992).

Potential changes to the structure of future TeamWork Project iterations were provided as well. Some families reported that they returned to old T1D habits after completion of their TeamWork sessions and had difficulty enacting long-term behavior change. These families may have benefited from additional materials to bolster intervention skills. For instance, “booster” phone calls between intervention sessions in the larger RCT were associated with ongoing engagement in the intervention (Sweenie, Herbert, Mackey, Holmes, & Striesand, 2012) and text messages have been shown to be a feasible tool to measure T1D regimen adherence (Mulvaney et al., 2012). These options were discussed positively by many families in this study and may be valuable tools to prevent the return to old, unhelpful habits.

Participants' insights into current T1D challenges provided additional suggestions for future TeamWork Project content. Topics included tips about balancing physical activity with BG management, good nutrition habits, tracking BG levels amidst families' busy schedules, stress management, communication with school personnel, increasing comfort with T1D management during peer activities, preparing extra paperwork for obtaining a driver's license, anticipating lows while driving, and managing T1D away from home (e.g. identifying accommodations at universities, selecting health insurance plans). Furthermore, participants wanted information regarding T1D complications that were targeted for an older adolescent population (e.g. sexual complications, independent hypoglycemia management) and reeducation about nutrition, T1D disclosure, and the biological mechanisms of T1D. Such topics may have either been unnecessary or inapplicable for younger children.

Participants reported high satisfaction with the structure and format of the TeamWork sessions, in particular, that they co-occurred with regularly scheduled endocrinology appointments. Thus future iterations of the program would likely benefit from using a similar format. However, there were varying opinions regarding whether or not parents and adolescents should meet together with the counselor or separately, when the program should occur with respect to the age of the adolescent and length of diagnosis, and the use of technology to enhance the program. Future program iterations could consider varying the format and timing of sessions to determine if participants perceive additional benefit from having separate sessions with a counselor and/or learning program skills closer to the time of diagnosis. Similarly, further evaluation of future interventions will help elucidate the benefit of including a technology component to determine if improvements are maintained longer if sessions are augmented by use of technology to booster program skills and techniques.

Strengths

The present study provides unique insights derived directly from parents and adolescents who participated in the Team Work RCT. Previous qualitative research with adolescents regarding T1D was either prospective, assessing issues in the "here and now" that could be incorporated into intervention development and/or clinical management, or retrospective, assessing participation in an intervention after its completion. In contrast, the study at hand addressed issues both prospectively, by addressing current issues for former RCT participants, *and* retrospectively, by assessing satisfaction regarding participation in an RCT. Participants were able to reflect on past experiences with the TeamWork Project to identify its strengths and weaknesses and discuss additional issues that should be addressed in a behavioral intervention for their current age group.

The study has several additional strengths. Namely, purposeful sampling of participants with varying changes in glycemic control (HbA1c increase, decrease, or no change) across the intervention ensured that data were representative of all potential perspectives from the RCT sample. Additionally, the study team interviewed both parents and adolescents to ensure that all participant perspectives were captured. Furthermore, the TeamWork Project was designed as the name suggests- to promote parent-adolescent collaboration with regard to

T1D management- so it was important to get opinions from both parents and adolescents when evaluating the intervention and planning for future iterations.

Limitations and Recommendations for the Future

Several weaknesses and areas for improvement should be noted. The present sample size represented a relatively small proportion ($n = 13$) of the total RCT participation ($n = 226$) and was primarily Caucasian, included a slight female majority, and most primary caregivers were mothers. Compared to the larger RCT, this sample had a higher percentage of Caucasian and female participants, and a lower percentage of mothers as primary caregivers. Furthermore, those families who were reachable may have had different opinions than families who could not be contacted by phone or who did not return the research team's voicemails. We applied common techniques used in qualitative research to establish trustworthiness and credibility (qualitative equivalents of validity and reliability) of these findings (Lincoln & Guba, 1985). We used a purposeful sampling method continuing until we achieved sufficient data saturation (i.e., interviewees provided redundant information) thus ensuring a broad range of perspectives and adequate number of interviews. We also carefully described our analytic procedures and provided detailed information about our code definitions including participant quotations. Although it is possible that our sample did not address the potential range of opinions about the TeamWork Project from the larger participant pool (i.e., it is possible that we did not comprehensively assess the opinions of male and non-Caucasian participants and missed crucial data that may improve the applicability of future interventions to the adolescent T1D population), the robust nature of sampling, data collection, and data analyses supports that these data effectively represent the sample and are likely applicable to other participants.

An additional consideration is that at least one year had elapsed since completion of the final TeamWork Project session for all participants. It is possible that the length of time that had elapsed since session completion may have impeded participants' ability to recall information about the program. We recommend that retrospective qualitative research be collected closer to the intervention completion date, if not collected concurrently, to ensure that participants can accurately recall intervention sessions.

Finally, interviewers experienced recorder errors for 3 interviews which is not atypical in field research. In fact some qualitative researchers have worked solely from field notes (Hinds et al., 2009). These 3 interviews were coded based on the interviewers' notes; however, it is possible that some points were missed. It is important to check recorder function immediately before beginning an interview and periodically during the interview. If the need arises to use field notes only, an additional step that can be taken to verify accuracy of the interview field notes transcript is to have the participant review the transcript and make needed changes.

Future Directions

Our findings suggest that it would be beneficial to incorporate mixed-methods into behavioral RCT design. By including qualitative evaluation, the research team could better understand how and why the intervention is efficacious or not. Results could be used to

make adjustments and improvements to the intervention (Buelow, 2007). Together, quantitative and qualitative findings may provide a richer, better understanding of intervention strengths and weaknesses as well as real-time assessment of intervention efficacy.

With respect to future iterations of the TeamWork Project, the information participants shared about their experience and current T1D challenges suggested that a continued emphasis on meeting with parent-adolescent dyads and discussing education, communication and problem solving is warranted to provide families with tools to ease the transition of T1D care from parent to adolescent, and from pediatric to adult endocrinology care. Additionally, recent T1D research has stressed the importance of including fathers (Dashiff, Morrison, & Rowe, 2008) and/or other caregivers (Monaghan et al., 2011) in interventions. Thus, future TeamWork Project iterations and evaluations should aim to incorporate communication and problem solving skills into education, increase the relevance of this program to a diverse participant range, and ensure that a wide range of participants are included.

Conclusion

The present study used qualitative research methods to assess participants' experiences with, and perceptions of, the TeamWork Project and identify concerns that adolescents and parents would like addressed in a similar program for same aged or older adolescents. Participants found the program beneficial and, in particular, believed that addressing challenges together as a dyad were crucial during the transitional adolescent years. They also discussed current issues, such as managing BG levels, driving, and reeducation, as well as the incorporation of health technology, to increase the relevance and benefit of such programs for an older demographic. Overall, findings highlight the utility of continued qualitative evaluation both during and after behavioral RCTs in order to best tailor them to the unique challenges related to pediatric chronic illness.

References

- American Diabetes Association. Standards of medical care in diabetes - 2013. *Diabetes Care*. 2013; 36(Suppl 1):S11–S66. [PubMed: 23264422]
- Anderson B, Brackett J, Ho J, Laffel L. An office-based intervention to maintain parent-adolescent teamwork in diabetes management: Impact on parent involvement, family conflict, and subsequent glycemic control. *Diabetes Care*. 1999; 22(5):713–721. [PubMed: 10332671]
- Buelow JM. An intervention for parents of children with epilepsy and significant learning problems: Lessons learned from a feasibility study. *Journal of the American Psychiatric Nurses Association*. 2007; 13(14):146–152.
- Cincotta, NF. The journey of middle childhood- Who are “latency-age” children?. In: Austrain, SG., editor. *Developmental Theories Through the Life Cycle*. 2 ed.. Columbia University Press; New York, NY: 2008.
- Dashiff C, Morrison S, Rowe J. Fathers of children and adolescents with diabetes: what do we know? *Journal of Pediatric Nursing*. 2008; 23(2):101–119. [PubMed: 18339336]
- DunnGalvin A, Gaffney A, Hourihane JO. Developmental pathways in food allergy: a new theoretical framework. *Allergy*. 2009; 64(4):560–568. [PubMed: 19154549]
- Greco P, La Greca AM, Ireland S, Wick P, Freeman C, Agramonte R, Skyler J. Assessing adherence in IDDM: A comparison for two methods. *Diabetes*. 1990; 40(Suppl 1):A165.

- Grey M, Boland E, Davidson M, Yu C, Sullivan-Bolyai S, Tamborlane W. Short-Term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care*. 1998; 21(6): 902–908. [PubMed: 9614605]
- Hampson SE, Skinner TC, Hart J, Storey L, Gage H, Foxcroft D, McEvilly EA. Behavioral interventions for adolescents with type 1 diabetes: How effective are they? *Diabetes Care*. 2000; 23(9):1416–1422. [PubMed: 10977043]
- Hartmann CW, Sciamanna CN, Blanch DC, Mui S, Lawless H, Manocchia M, Pietropaoli A. A website to improve asthma care by suggesting patient questions for physicians: Qualitative analysis of user experiences. *Journal of Medical Internet Research*. 2007; 9(1):e3.
- Hinds P, Oakes L, Hicks J, Powell B, Srivastava K, Spunt S, Furman WL. “Trying to be a good parent” as defined by interviews with parents who made Phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*. 2009; 27(25):5979–5985. [PubMed: 19805693]
- Hsieh HF, Shannon S. Three approaches to qualitative content analysis. *Qualitative Health Research*. 2005; 15(9):1277–1288. [PubMed: 16204405]
- Johnson SB, Kelly M, Henretta JC, Cunningham WR, Tomer A, Silverstein JH. A longitudinal analysis of adherence and health status in childhood diabetes. *Journal of Pediatric Psychology*. 1992; 17(5):537–553. [PubMed: 1432480]
- Lincoln, Y.; Guba, E. *Naturalistic inquiry*. Sage Publications; Newbury Park, CA: 1985.
- Mackey ER, Hilliard ME, Berger SS, Streisand R, Chen R, Holmes C. Individual and family strengths: an examination of the relation to disease management and metabolic control in youth with type 1 diabetes. *Families, Systems, & Health*. 2011; 29(4):314–326.
- Martin M, Beebe J, Lopez L, Faux S. A qualitative exploration of asthma self-management beliefs and practices in Puerto Rican families. *Journal of Health Care for the Poor and Underserved*. 2010; 21(2):464–474. [PubMed: 20453350]
- Monaghan M, Sanders RE, Kelly KP, Cogen FR, Streisand R. Using qualitative methods to guide clinical trial design: Parent recommendations for intervention modification in Type 1 diabetes. *Journal of Family Psychology*. 2011; 25(6):868–872. [PubMed: 21668118]
- Mulvaney SA, Rothman RL, Dietrich MS, Wallston KA, Grove E, Elasy TA, Johnson KB. Using mobile phones to measure adolescent diabetes adherence. *Health Psychology*. 2012; 31(1):43–50. [PubMed: 21967662]
- Price CS, Corbett S, Lewis-Barned N, Morgan J, Oliver LE, Dovey-Pearce G. Implementing a transition pathway in diabetes: A qualitative study of the experiences and suggestions of young people with diabetes. *Child: Care, Health, & Development*. 2011; 37(6):852–860.
- Sandelowski M. Focus on qualitative methods: Using qualitative methods in intervention studies. *Research in Nursing and Health*. 1996; 19(4):359–364. [PubMed: 8773558]
- Sandelowski M. Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in Nursing and Health*. 2000; 23(3):246–255. [PubMed: 10871540]
- Sweenie, R.; Herbert, LJ.; Mackey, ER.; Holmes, C.; Striesand, R. Use of booster calls in a behavioral intervention for adolescents with type 1 diabetes.. Poster presented at the 4th Annual mHealth Summit; National Harbor, MD. 2012.
- Wiebe DJ, Berg CA, Korbel C, Palmer DL, Beveridge RM, Upchurch R, Donaldson DL. Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology*. 2005; 30(2):167–178. [PubMed: 15681311]
- Wysocki T, Harris MA, Greco P, Bubb J, Danda CE, Harvey LM, Sadlet M, White NH. Randomized, controlled trial behavior therapy for families of adolescents with insulin-dependent diabetes mellitus. *Journal of Pediatric Psychology*. 2008; 25(1):23–33. [PubMed: 10826241]

Table 1

Themes, Codes, Definitions, and Examples

Theme	Code	Definition	Example
TeamWork Content	Reinforcement	TeamWork program supported or helped parent/teen continue using current T1D-related knowledge or skills	Parent: "[TeamWork] reaffirmed what I was doing- that I was trying to do T1D management right."
	Communication and Problem-Solving	Teamwork program encouraged/supported family members in efforts to talk with each other effectively and work together and to develop and implement solutions to T1D-related or non-T1D-related concerns	Teen: "I remember the packet for the problem solving stuff the most and we have those magnets on our fridge... We have a lot of arguments in my family, so I think having the chance to talk about ways to fix it [was helpful]."
	New Perspectives and Skills	TeamWork program helped family think about T1D in a new way (either from the counselor or by understanding parent/teen's experiences) and/or taught new techniques to manage T1D	Parent: "Having [my daughter] hear certain things that I may have said from another adult or from another perspective, so that she doesn't feel like I'm ramming it down her throat [was helpful]. Same for me; me hearing her perspective."
	Program was Beneficial	TeamWork program was relevant and helpful	Teen: "I found that talking through stuff, especially with my mom through this program, has helped me to handle situations with my dad also."
TeamWork Structure	Return to Old Habits	After learning TeamWork program skills, families usually engaged in previous T1D behavior patterns and needed reminders to continue using program skills	Parent: "It's easy to hear it and even to gain from it, but I think it's easy to slip back into old patterns and forget."
	Session Structure and Timing	Content included in the intervention training components, the set-up of the individual meetings, and the co-occurrence of meetings during clinic were appropriate, though dyads had mixed opinions regarding meeting together.	Teen: "I liked it in the sense that... she was there to hear what I needed to say and hear what I was fearing and all that stuff. But I didn't like it because if she felt that I said something wrong, then she would, like jump on me, and it's like- this is not your session."
	Varying T1D Program Needs	In general anyone can benefit from the program, though specific needs of youth with T1D is dependent on several factors, including youth's age, length of diagnosis, and glycemic control	Parent: "Just because you're a person who has a good control of the diabetes, it doesn't mean they can't learn something from it. I mean, even for somebody like us who was diagnosed as a baby, to somebody who was diagnosed as a teenager. I think it would be good for everybody."
	Allocation of T1D Care Responsibility	Teen is primarily accountable for T1D management, but parent(s) monitors teen's behavior and parent/teen work together	Teen: "Ninety-eight percent of the time I am doing all of my sugar checks and all of my shots. It's only in that 2% that I'll say maybe I'm dizzy or I had a late meal or whatever, so eating and shot checking myself is off."
Current and Future Challenges	Physical Activity	Exercise complicates T1D management, but teens' T1D can also benefit from regular exercise	Teen: "When I am active, my blood stays down low where it's supposed to be."

Theme	Code	Definition	Example
	Nutrition	Making food choices is challenging and some teens engage in disordered eating	Parent: "We're constantly adjusting, trying to come up with new menus and things that work."
	BG Management	Teens have difficulty regulating BG levels, identifying BG patterns, and taking insulin appropriately	Teen: "...my numbers seem to go haywire sometimes."
	Stress	Mood and the need to cope daily with T1D impact T1D management; T1D, in turn, impacts mood and coping	Teen: "Sometimes, it may not be the sugar itself; it's just my realization that I have it. It would be just one of those days I have diabetes, woe is me."
	School	Educators are often supportive of T1D needs, but T1D management in the academic setting can also be difficult	Teen: "There was a health aid and she'd say things to me like, 'Diabetics don't go low when they exercise. There must be something wrong with you.' I was just, like, this is the person in charge of my healthcare. I'm scared."
	Social Support	It can be difficult to manage T1D during peer activities, though in general, peers are knowledgeable and supportive of T1D management	Parent: "That's the hardest thing – when she's in a situation when she doesn't have as much control over choices as she does at home or elsewhere."
	Driving	Accommodations are required when getting a driver's license and teens have to appropriately manage low BG levels when operating a car	Parent: "So far, we've had to fill out paperwork twice since he's gotten his license, because you have to keep getting paperwork resigned by your doctor and submitted back through the medical board and sending it through so it's very frustrating."
	Post-High School Plans	T1D has varying impact on plans for school or work after graduation	Parent: "We're not comfortable with him going out on his own yet - going away for college. So he's going to be doing...at least a year of junior college here still living at the house before we feel comfortable with him going away."
Future Intervention Considerations	Reeducation/Psychology	Additional information about T1D itself as well as about management and complications is important; Regular mental health check-ins would be beneficial for families	Parent: "I think just about everything in the world would benefit from general therapy. I think the specific challenges of having a diabetic teen, having someone to bounce things off of is really helpful."
	T1D-related Technology	T1D websites, text message programs, and smartphone apps may be beneficial	Teen: "I read some like blogs about diabetes that are kind of cool, like different people sharing their stories."