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Perceptions of Type 1 Diabetes among Affected Youth and their Peers

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Abstract

Management of type 1 diabetes (T1D) involves balancing several components including diet, exercise, and medication. Peer involvement in management tasks is an important, but understudied, issue in T1D. This study presents results of a preliminary examination of perceptions of disease management in youth with T1D and their peers. Data were collected using a mixed methods (qualitative and quantitative data) approach during medical education time at a camp for youth with T1D and their peers. Results suggest that both youth with T1D and their peers believe that peers need more information about medical consequences of having diabetes. Further, youth with T1D and their peers would like coaching on how peers may help the child with T1D manage their illness better. Results provide preliminary ideas for intervention (i.e., including peers, assessing social support) in the medical setting as well as ideas for future research (i.e., examining relationships among perceptions and gender, time since diagnosis).

Keywords

Type 1 Diabetes; Adolescents; Peers

Introduction

Type 1 Diabetes (T1D) is one of the most common childhood chronic illnesses (CDC, 2005) and involves a complex daily regimen. Although regimen adherence is critical for preventing negative health outcomes, it has been well documented that many adolescents are nonadherent (e.g., Hoffman, 2002). Various factors have been associated with nonadherence, including physiological changes due to puberty (e.g., Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986), diabetes knowledge (e.g., La Greca, Follansbee, & Skyler, 1990), and psychological problems (e.g., La Greca, Swales, Klemp, Madigan, & Skyler, 1995).

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Adolescence is a time in which peer relationships become increasingly important as family relationships change (e.g., Collins, Gleason, & Sesma, 1997) and regimen adherence declines (Kovacs et al., 1997). Thus, although peer relationships during adolescence are important (La Greca, 1992), few studies have directly examined the role of peers in adolescents' regimen adherence (e.g., Bearman & LaGreca, 2002). In one review, LaGreca et al (2002) reported that peer support can promote better adjustment to chronic illness and may improve adherence to medical recommendations. Conversely, Delameter, Smith, Kurtz, and White (1988) found that adolescents reported more difficulty adhering to their regimens in social situations with peers. In a study of adolescent adherence choices, Thomas, Peterson, and Goldstein (1997) reported that adolescents use higher problem-solving abilities, but still choose non-adherent behaviors when in social situations. They interpreted results to be reflective of typical development, as social desires become more influential during this developmental period (Collins, Gleason, & Sesma, 1997). Another study (Haines, Patron, Berlin, Alemzadeh, & Davies, 2006) suggested that when youth make negative attributions about their friend's responses to regimen tasks they are less likely to engage in them and subsequently miss opportunities to engage their friend's support.

Several studies have examined the positive aspects of peer responses to an adolescent with a chronic illness. Peer relationships provide companionship as well as emotional support for adolescents, which can be particularly important for adolescents with a chronic illness (LaGreca et al., 1995). In one study (Shroff-Pendley et al., 2002), adolescents perceived greater diabetes-related peer support relative to school-age children. However, adolescents with diabetes often cite peer support as an area that they would like to enhance (e.g., Nabors, Lehmkuhl, Christos, & Andreone, 2003). A study by Greco and colleagues (2001) demonstrated improved social support for the diabetes regimen following a group educational intervention for youth with T1D and a peer.

Previous literature has examined variables that might improve adherence in social situations, (e.g., positive peer relationships Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007; LaGreca, Bearman, & Moore, 2002). For example, Greco and colleagues (2001) demonstrated that an educational intervention for youth with T1D and their peers improved knowledge, social support, and decreased familial conflict – all factors related to adherence. However, little attention has been paid to the attitudes of peers' opinions of diabetes and the impact of these opinions on diabetes management. To the best of our knowledge, no quantitative studies have examined this directly. Due to the exploratory nature of the goals of this study, qualitative methods were chosen. Qualitative methods allow for development of hypotheses about children's opinions on a sensitive topic. Additionally, using open ended questions allows children to feel comfortable when responding and may elicit more subtle opinions (Krahn & Eisert, 2000). Responses are typically recorded verbatim and reviewed using a coding strategy determine themes (e.g., Grounded Theory, Strauss & Corbin, 1990). In addition to the qualitative data, the present study incorporated quantitative data about children's perceptions in order to augment the qualitative. This type of mixed methods approach provides the most comprehensive picture of children's attitudes and opinions about sensitive topics such as having a chronic illness like diabetes (e.g., Heary & Hennessy, 2002). Thus, we believe that this methodology would be the most appropriate to begin to gather preliminary information about youth and peer attitudes toward T1D which could be used to generate testable hypotheses in future studies.

The present study is an exploratory examination of adolescents' with T1D and their friends' attitudes about diabetes and perceptions of peer influences on managing diabetes. We believed that affected youth and their peers may have similar attitudes about T1D. Due to the exploratory nature of the study, directional hypotheses were not made. Unique features of this study included use of a mixed methods approach and inclusion of adolescents' peers. This study

utilized the forum of a camp for youth with diabetes and their peers for data collection. This camp serves 1100 youth with diabetes annually. Camp is available to any youth with T1D, regardless of their ability to pay. As there is little information regarding the attitudes of youth with T1D and their peers toward diabetes, this particular camp was an ideal setting in which to obtain preliminary data. This camp provided an opportunity to obtain information from a group of youth with T1D and their peers about their attitudes toward T1D.

Method

Participants

Participants included 70 adolescents (71% female) between the ages of 11 and 16 attending a weekend diabetes camp. Of these, 45 had T1D (29 girls 64%; 16 boys 36%) and 25 were peers of the children with T1D (20 girls 80%; 5 boys 20%). Peers were a similarly aged and same gender child that the youth with T1D identified to bring. Relatives were not permitted. Youth attend camp on a voluntary basis. To help maintain anonymity of the respondents, campers were not asked to divulge ethnicity. Thus, aside from gender, no demographic information was obtained from individual campers and could not be linked back to individual forms. Aggregate data on demographics obtained from enrollment statistics revealed that 87.5% were Caucasian, 10% Hispanic, and 2.5% African American. This is similar to the most recently available national data (LaPorte, Matsushima, & Chang, 1995) which reports that 86% of youth with T1D are Caucasian, 5% Hispanic, and 8% African American. Thus, our sample is ethnically similar to national statistics. Information regarding time since diagnosis was not available. Average HbA1c for campers with T1D (including the two youth with T1D who did not participate), obtained from intake statistics, was in the average range ($M = 7.88$, $SD = 1.37$, range = 5.2 to 11). Only three youth (2 with T1D and 1 peer) that attended camp did not participate in the study (96% completion rate). As no demographic data were collected on individual participants, it was not possible to compare youth who completed and did not complete the measures nor between those who brought a peer and those who did not.

Procedures

Institutional review board approval was obtained from the University of Florida for these procedures. Camp administration asked that names and identifying information was not obtained. Due to this stipulation, the present study was considered exempt. Campers included youth with T1D and a peer of the same age and gender. Youth with T1D did not have to bring a friend to participate in camp, but were encouraged to do so. Data was obtained during medical education time. Campers completed medical education time in two sessions, youth with T1D discussed medical advances in diabetes management and peers learned basic diabetes information. This time was chosen as it provided for the most available time without taking away from other activities and was chosen by camp administration. The first author was present to describe study procedures, administer surveys to youth, and answer any questions or address concerns. The study and measures were described as a way to obtain more information about perceptions of diabetes for youth and peers. Campers were assured that information would not be shared and that identifying information was not collected on the surveys. After explaining the study to youth, the first author distributed surveys and youth completed them. No youth asked any questions and no one objected to completing measures. Three measures were returned blank, but no reason for non-completion was given.

Measures

Talking about Diabetes Survey, Adolescent and Peer Versions (TADS-A; TADS-P)—The TADS-A and TADS-P were developed as qualitative measures for this study to assess perceptions of youth with T1D about the roles peers play in managing their illness. Questions were developed by the first and second author based on clinical experience working with youth

with T1D. The TADS-P was developed concurrently to assess peers' perceptions of their friends with diabetes. Youth with T1D answered 12 free response items about completing management tasks while spending time with peers. Peers responded to similar questions (14 items). Youth with T1D also completed four questions indicating how much diabetes keeps them from engaging in social and school activities, working, and dating. Peers completed similar questions indicating how much their friend's diabetes interrupted several activities. Both sets of items used 4 point Likert scales (1 = "not at all," 2 = "a little bit," 3 = "most of the time" 4 = "completely"). Psychometric data are not available for qualitative items. For the quantitative questions, Cronbach's alphas were .71 for youth with T1D and .80 for peers. Questions for each measure, along with sample responses, are presented in Table 1.

Data Analysis

The Grounded Theory method of constant comparative analysis was used to analyze free response data (Strauss & Corbin, 1990). In the grounded theory approach, qualitative data is reviewed to reveal themes and generate theories to explain the data rather than beginning with a testable theory. This methodology was chosen due to the exploratory nature of the study. It was believed that grounded theory would best condense the data and provides theories for use in constructing testable hypotheses for future work. The first step in grounded theory is to review all the responses using an open coding method. Review of the responses leads to identification of themes that best describe the data. For this study, the first and second author reviewed the responses. Next, themes were discussed to consensus, so that both authors agreed on which themes best described the data and which comments fit with which theme(s). Finally, a second party, who was blind to the first and second authors' assignment of responses and who had considerable diabetes knowledge, placed each response into a theme category to determine reliability. To examine reliability, the percent agreement [(number of agreements/total decisions) × 100] was used. The percent agreement for the present study was 87%. Quantitative items on the TADS-A/P were analyzed by examining the mean response for each item for adolescents and peers separately.

Results

Attitudes about Diabetes

Youth with T1D reported that they would like peers to know about the cause of T1D (26%, $n = 12$) and understand dietary restrictions (21%, $n = 9$). Fewer youth would like peers to recognize the emotional consequences of having T1D (7%, $n = 3$). Approximately one third stated that their friends were sympathetic (32%, $n = 14$) when learning of their diagnosis. While a smaller percentage indicated that peers thought that having T1D was "cool" or "interesting" (16%, $n = 7$).

Approximately 12% of peers reported being interested in the medical facts of having T1D ($n = 3$), experience of having T1D (24%, $n = 6$), and information related to the required regimen (16%, $n = 4$). Peers reported feeling empathy (32%, $n = 8$) when learning about their friend's diagnosis. Others admitted feeling curious (16%, $n = 4$), while a third had no strong response (32%, $n = 8$).

Social Consequences of Having Diabetes

Approximately 30% of youth with T1D reported that explaining T1D was the most difficult part of telling friends about it ($n = 13$); though discussing the consequences of having T1D was also reported as being a potential stressor (20%, $n = 9$). They also noted that their regimen interferes with social activities by making them feel different from their peers (31%, $n = 14$), wasting time or interrupting activities (29%, $n = 13$), and not being able to participate when friends are eating (22%, $n = 10$). In terms of making new friends, most youth with T1D reported

that having T1D did not interfere (68.8%, $n = 31$). In fact, two adolescents noted that having T1D *helped* them to make friends.

Peers stated that concern about the consequences of having T1D was the most distressing to them (40%, $n = 10$). Many stated that regimen activities did not interfere with social activities (48%, $n = 12$); however, “taking time away from activities” (32%, $n = 8$) was the most commonly reported diabetes-related problem.

How Friends [Can] Help with Management

Youth with T1D most commonly reported that nothing changes in their self-care while with peers (66.7%, $n = 30$). However, they reported that peers could provide verbal reminders to complete regimen tasks (32.8%, $n = 21$), help monitor symptoms of hyper/hypoglycemia (9.3%, $n = 6$), and provide general assistance with regimen tasks (e.g., getting supplies, 7.8%, $n = 5$). Approximately two thirds of the youth with T1D ($n = 27$) reported that peers did not need to make any changes. Those who identified potential areas for improvement, cited reminders (7.8%, $n = 5$) and not “making a big deal” about their diabetes (4.6%, $n = 3$) as ways their friends could improve. Peers believed they could help their friend manage his/her T1D by providing reminders (52%, $n = 13$) or assisting with other tasks (24%, $n = 6$). A smaller group identified providing emotional support (12%, $n = 3$) or monitoring symptoms (8%, $n = 2$) as additional ways to help friends.

Quantitative Data from the TADS-A/P

Adolescents responded to four questions about how much their diabetes interfered in different areas of their lives. Youth with T1D reported that diabetes did not interfere much with spending time with friends ($M = 1.72$, $SD = .66$), participating in school activities ($M = 1.70$, $SD = .74$), working after school ($M = 1.44$, $SD = .67$), or dating ($M = 1.38$, $SD = .62$).

Peers responded similarly about how much their friend's diabetes got in the way of doing things at school ($M = 1.54$, $SD = .66$), when the affected youth was at a friend's house ($M = 1.44$, $SD = .51$), when the peer is at the affected youth's house ($M = 1.60$, $SD = .71$), at after-school activities ($M = 1.83$, $SD = .82$), and on weekends ($M = 1.58$, $SD = .65$).

Discussion

This study is a preliminary examination of the attitudes of youth with T1D and their friends regarding how having diabetes impacts their lives and social relationships. We sought to begin to describe factors concerning youth with T1D and provide information that may be used in designing interventions to improve adherence to the diabetes regimen. To our knowledge, this is the first qualitative study of the perceptions of youth with T1D and their peers.

Results suggest that a few youth with T1D and their peers believe that the non-affected youth need more information about the medical responsibilities of having diabetes. However, some youth identified telling peers about diabetes as a potentially difficult task. This suggests that teaching youth how to communicate effectively with peers regarding their illness may be an area for improvement in diabetes care. Perhaps providing education in the classroom or in a camp setting, where youth with T1D and their peers could receive information regarding the basics of diabetes management (Nabors et al., 2003) would reduce the burden on affected youth.

In terms of management, youth denied that being with friends affected their ability or willingness to complete their self-management tasks. Peers corroborated this report as did the quantitative data. However, between 20 and 30% of affected and non-affected youth acknowledged that completing diabetes related tasks disrupted social activities and took time away from being with friends. It may be that youth overestimate the time they engage in

management activities with friends. It would be interesting to compare the time youth spend managing their diabetes during an activity to the perception of time spent. Another possible explanation is that youth with T1D do believe that their management gets in the way of social activities because they are nonadherent to the regimen. While the present sample is in relatively good control, it would be interesting to determine if there are differences based on glycemic control. These hypotheses are clinically relevant, as previous research has suggested that social pressures may influence disease management (Hains, Berlin, Davies, Parton, and Alemzadeh, 2006). In the future, it will be important to include in vivo observations to assess differences in regimen compliance when youth with T1D are alone or with peers. Both youth with T1D and their peers indicated that friends can assist with adherence by providing reminders to check blood glucose and administer insulin. During adolescence, peer group support becomes more important to adolescents (Shroff-Pendley et al., 2002). Thus, clinicians may want to consider peers when making recommendations for a treatment regimen. Perhaps, in some cases, it would be helpful for a close friend to attend a clinic visit with the affected youth, in order to learn ways that they might assist their friend. Greco and colleagues (2001) conducted a group intervention for youth with T1D and their peers. Their intervention focused on improving diabetes related knowledge and increasing social support for youth around the diabetes regimen. They found that this improved knowledge and social support. Combined with results from the present study, this provides strong evidence that peers may be a key component to adherence with the diabetes regimen.

Results of this study contribute to the literature on children's perceptions of diabetes, but some limitations should be noted. First, participants were recruited from a camp for youth with T1D. Perhaps youth attending this camp have more positive attitudes toward T1D than the general population. Similarly, the relatively low number of participants, and in particular males, limits the extent to which results can be generalized. It may be that boys and girls have different needs for and experiences of friendships (Helgeson et al., 2007); thus this should be examined directly in the future. The sample was also in overall good glycemic control (average A1c = 7.88); perhaps youth who are in better control have more positive perceptions of their illness and its management. It will be important to examine perceptions of youth in poor glycemic control. Second, in order to help maintain anonymity of the respondents, the demographic information of study participants was not obtained on study measures, but obtained from camp statistics. This prevented analyzing data by ethnic group and limited the number of analyses that could be conducted, as data could not be matched to response on study measures. It will be important to obtain this information in future studies. Perhaps perceptions of illness would vary based on the ethnicity of the respondent. The primary goal of this study was to begin to describe the attitudes of affected youth; thus, despite these limitations, results from this study provide preliminary descriptive data that may be used to design prospective studies in the future.

This study examined attitudes of youth with T1D and their peers regarding how diabetes impacts their lives and social relationships. As this was an exploratory study designed at gathering information for generating hypotheses in the future, youth responded to targeted questions about difficulties. While this may have influenced their responses to some degree, it provides the literature with needed information about potential barriers to adherence. Clinically, results of this study suggest that psychologists working in a medical setting or clinic should examine the role of peer support on the diabetes regimen. Perhaps incorporating a peer into the diabetes management plan may improve adherence to the regimen (LaGreca, Bearman, & Moore, 2002). Further, educating youth with T1D about how to talk to peers about their illness may reduce some of the strain these youth experience when explaining their disease to peers. Additionally, it points to the clinical importance of assessing the individual's need for social support as not all youth in the study reported a desire for additional peer involvement. In terms of future research, it will be important to address the limitations listed above in future studies and to use the information obtained here for hypothesis driven studies. For example,

do attitudes toward peer support vary as a function of gender (with girls experiencing more support Helgeson et al., 2007), glycemic control, length of time since diagnosis, and ethnicity. Results from this study should be used to examine how some of these potential barriers may affect adherence to the regimen in these youth.

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Table 1
Items and Sample Responses from the TADS-A

TADS-A Items	Representative Comments
1. What is the hardest part about having diabetes when you are with your friends?	"Time it takes away from being with them. It singles you out. They try to tell you what you cannot do."
2. What would you like your friends to know about having diabetes that they DON'T know?	"You can have sugar...its not all sugar free."
3. What do your friends say about you having diabetes?	"They don't really care, sometimes they have questions, but I don't mind (most of the time)."
4. What's the hardest part of telling your friends about your diabetes?	"Some people just stop talking to me." "They might not think of you the same, if they know."
5. How does having diabetes get in the way of having fun with friends?	"You can't just eat or drink whatever you want." "Takes too much time."
6. How does having diabetes get in the way of making friends?	"It's just hard to tell them why I have to do some of the things I do."
7. Are there any differences in your management when you're with friends?	"I sometimes forget about it when I am with them."
8. How do your friends help you manage your diabetes?	"They ask if I have checked my sugar."
9. What can your friends do differently to help with your diabetes management?	"Help me with stuff." "Remind me to test."
10. How do your friends make it harder to follow your regimen?	"They sometimes hurry me and don't want to be patient enough to let me bolus or check."
11. Does it bother you to take care of your diabetes in front of your friends? Explain.	"They don't normally pay attention, most of them don't like blood."
12. Does it bother you when your friends are eating/doing things you can't do because of your diabetes? Explain.	"Sometimes it bothers me when they do something I can't."

Table 2
Items and Sample Responses from the TADS-P

TADS-P	Representative Comments
1. What are the hardest parts about having a friend with diabetes?	"Nothing, they are pretty much just like me."
2. What do you like about your friend's diabetes?	"I get to learn more about diabetes."
3. What do you wish you knew about having diabetes?	"To know what to do in every situation just in case."
4. How did you feel when you found out your friend had diabetes? Why?	"I thought it was sad, but I knew we would still be close friends."
5. What do other kids think about your friend's diabetes?	"They think its cool."
6. How does your friend's diabetes get in the way of having fun together?	"Other than her briefly testing herself, it doesn't make a difference."
7. Does it bother you that your friend has diabetes? Why or why not?	"Sometimes it does, because I'm scared she will get too much insulin or not enough."
8. How is your friend different because s/he has diabetes?	"She isn't different. She just needs to test herself and regulate her blood sugar."
9. How do you help your friend take care of his/her diabetes?	"I remind her to test after eating and stay with her when she does."
10. Does your friend ask you NOT to help with his/her diabetes? What does s/he ask you NOT to do?	"She tells me not to mess with her medicine."
11. If you could change one thing about your friend's diabetes, what would you change?	"That she didn't have to stick herself with a needle." "Taking medicine."
12. How do your parents treat your friend with diabetes differently from your other friends?	"They treat her the same." "My mom treats my friend the same as anyone else."
13. Does it bother you when you do/eat something that your friend with diabetes can't? Explain.	"I don't eat it if she can't have it." "Yes, because she might miss something good."
14. Does it bother you to see your friend doing something to take care of his/her diabetes? Explain.	"No, she does what she needs to." "Sort of since they have to take shots."