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Management of Cardiovascular Disease Risk in Teens with Type 1 Diabetes: Perspectives of Teens With and Without Dyslipidemia and Parents

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Abstract

Hypertension and dyslipidemia are often suboptimally managed in teens with type 1 diabetes (T1D). Teen and parent perspectives on hypertension and dyslipidemia management need further study in order to enhance the development of CVD risk factor management plans. We sought to describe barriers to and strategies for CVD risk factor management.

Teens with T1D with and without dyslipidemia and parents of teens with T1D with and without dyslipidemia underwent one-on-one semi-structured interviews conducted by trained personnel at a diabetes center; interviews continued until thematic saturation was reached. Teens and parents of teens described their knowledge, attitudes, and beliefs regarding heart health and CVD risk factors (hypertension and dyslipidemia). Researchers undertook a content analysis and categorized central themes as strategies and barriers.

In total, 22 teens and 25 parents completed interviews. Teens were 17.4±1.7 years old with T1D duration 9.7±4.0 years; 45% had dyslipidemia. Parents were between 41–60 years old, 84% were mothers, and 40% had teens with dyslipidemia. Barriers to heart health included an obesity-promoting environment, parental distrust of medications, and limited teen knowledge about hypertension and dyslipidemia. Strategies included specific and realistic guidance from providers, family support of teen lifestyle management, and having exercise partners. While teen and parent perspectives were often similar, some themes applied only to teens or parents.

Central themes provide actionable guidance to enhance hypertension and dyslipidemia management. Providers should consider teen and parent perspectives when managing CVD risk factors in order to enhance engagement with CVD risk management.

Keywords

Diabetes Mellitus, Type 1; Hypertension; Dyslipidemias; Adolescent Health

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Introduction

Guidelines recommend aggressive management of cardiovascular disease (CVD) risk factors such as hypertension and dyslipidemia in teens with type 1 diabetes (T1D). Most commonly cited guidelines (1–4) recommend heart healthy dietary changes and aerobic exercise prior to or concurrently with medication initiation for these conditions. However, studies demonstrate that many teenagers with T1D are not currently meeting blood pressure or lipid targets(5, 6), perhaps in part because current strategies to encourage heart healthy behaviors or regular medication use are ineffective.

Most pediatric diabetes providers initially recommend lifestyle changes for management of hypertension and dyslipidemia and yet they describe lifestyle counseling as often ineffective(7). In order to improve the efficacy of provider counselling and inform the design of interventions to increase heart healthy behaviors in teens, teen knowledge of CVD risk factors and attitudes and beliefs for different management strategies needs further study.

This qualitative study assesses barriers to and strategies for developing heart healthy lifestyle behaviors in teens with T1D. This study further explores attitudes surrounding lipid-lowering and anti-hypertensive medications, a potentially significant factor in the limited uptake of these medications for teens with future CVD risk.

Methods

Participants

In this qualitative study, participants were teens and parents from a diabetes center. Inclusion criteria included being a teen with T1D or parent of a teen age 13–19 years old with T1D for at least one year. In order to ensure inclusion of teens with elevated CVD risk in addition to teens without elevated CVD risk, teens with dyslipidemia and parents of teens with dyslipidemia were purposefully sampled in order to provide a greater diversity of viewpoints. Dyslipidemia was defined as a diagnosis of dyslipidemia found in the teen's electronic health record, which typically indicated a current or previous elevation in LDL cholesterol levels. The study was approved by the Institutional Review Board (IRB) and informed consent/assent was obtained from all study subjects before participation; procedures were in accordance with the Declaration of Helsinki.

Recruitment

Participants were recruited at the time of their regular clinic visit. Parent participants and teen participants over the age of legal consent provided informed consent, and minor teens provided assent. Participants provided demographic information by completing a questionnaire. Interviews occurred at the time of diabetes clinic visits or by phone. Recruitment of participants continued until saturation of themes was reached in the qualitative interviews. Data saturation was considered separately in participants with and without dyslipidemia.

Data Collection

A multidisciplinary team including pediatric diabetes physicians, diabetes nurse educators, pediatric psychologists, data analysts, and research assistants designed and refined the interview script. The interview script consisted mostly of open-ended questions with probes to be used as needed to encourage full participant responses (scripts available on request). Three research staff members received interview training and then conducted semi-structured interviews. Interviews were conducted separately for parents and children. Interview duration was variable, ranging from 15–60 minutes. Interview sessions were conducted privately, either in-person (n=28) or by phone (n=19). Interviews were audio recorded for later transcription.

In teens, lipid-lowering medication use, educational level, and family history of hypertension, dyslipidemia or CVD were obtained by chart review. A1c and LDL levels reflected the most recent value reported in the participant's chart. A1cs were obtained as a part of routine, clinical care typically on the day of consent for the study.

Data Analysis

Interviews were professionally transcribed by a HIPAA compliant transcription company (Landmark Associates Inc.) and de-identified. Research team members had training in qualitative methods and backgrounds in pediatric diabetes, psychology, and public health. Analysis included first cycle and second cycle coding(8).

In the first coding cycle, the three study team members coded five transcripts independently and then all members met to discuss codes and develop or revise a coding list. The coding list consisted of ideas and phrases that naturally emerged from the transcripts and were used to organize and group the data from the transcripts. Coding was compared among coders and discrepancies were resolved through discussion and consensus among the research team. Additional transcripts were coded and reviewed by study team members as needed to establish strong inter-coder reliability through review, discussion, and feedback. In the second coding cycle, study team members used NVivo version 11.2 (QSR International Pty Ltd.) to apply codes from the established coding list to relevant quotations. The remaining transcripts were double-coded and discrepancies were resolved by the three-person team.

A content analysis of codes was conducted to summarize central themes from the qualitative data. Team members utilized a focusing exercise in which codes were grouped into clusters and the clusters were analyzed to determine important beliefs, emotions, and actions as well as similarities and differences between parent and teen responses. Central themes were then derived by each study team member and differences in the themes were resolved by discussion until a list of the most salient themes emerged.

We approached data triangulation in two ways. First, we sought to include different perspectives on heart healthy knowledge, attitudes, and beliefs by interviewing teens and parents as well as teens or parents of teens with and without dyslipidemia. We examined whether themes were the same or different across different subgroups. Second, we solicited diverse perspectives by presenting our initial themes and representative quotes to a broader research group consisting of two pediatric endocrinologists, two psychologists, and a data

analyst (all experienced with qualitative research) who provided input and feedback leading to minor revisions of our thematic classification.

After developing our list of themes, we characterized major themes into barriers to and strategies for adopting heart healthy behaviors according to parent and teen perspectives. Themes that were not seen as strategies and barriers by participants but rather by the study team are also included.

Results

Participant Characteristics

In total, 22 teens and 25 parents completed interviews (Table 1) including 18 parent-child dyads. Teens were age 17.4 ± 1.7 years with T1D duration 9.7 ± 4.0 years; 45% had dyslipidemia. Two-thirds (68%) were female and 82% were non-Hispanic white. No teen participant had been diagnosed with hypertension.

Parents were between 41–60 years of age and most (84%) were mothers. Most parents (72%) worked full time or part time, 88% were non-Hispanic white, and 63% had a college or graduate degree. Forty percent of parents ($n=10$) had teens with dyslipidemia.

Barriers to Heart Health

The study team identified five barriers to heart health (Table 2). Parents and teens were in general agreement about two commonly endorsed barriers, “Pervasiveness of Unhealthy Options” and “Negative Influence of Peers and Family”. The study team identified additional barriers: “Limited Teen CVD Risk Factor Knowledge”, “Parental Distrust of Medications,” and “Teen Focus on the Present.” Related themes and quotes are described in Table 3. Among these barriers, the most commonly endorsed related to limited CVD risk factor knowledge (particularly in teens), distrust of medications (particularly in parents), and pervasiveness of unhealthy food options in both teens and parents.

Pervasiveness of Unhealthy Options

An area of consensus between teens and parents was the impact of pervasive unhealthy food choices on healthy eating. Teens mentioned a plethora of unhealthy food environments including their schools, colleges, homes, friends’ houses, fast food restaurants, and convenience stores. Teens focused more on various food environments with or without the presence of peers while parents focused more on situations where peers were present.

Negative Influence of Peers and Families

Parents and teens acknowledged a major influence of peers in influencing poor teen food choices. A couple of teens thought that their family’s unhealthy choices also hindered their enacting heart healthy changes while parents did not acknowledge their influence as potentially unhelpful.

Teen CVD Risk Factor Knowledge Gap

Most teens had limited knowledge of hypertension, and some teens, especially those without dyslipidemia, had limited knowledge regarding elevated cholesterol levels while others were more knowledgeable. Teens rarely mentioned the connection between hypertension and the heart and many used only generalities when speaking about hypertension.

In contrast, parents had reasonable knowledge of hypertension and high cholesterol and acknowledged their connection to CVD. Parents' knowledge of hypertension was generally less specific than their cholesterol knowledge with some parents resorting to generalities such as "*It's not good.*" Many parents identified the link between hypertension and CVD and cited lifestyle changes and medications as options for treating hypertension. Most parents readily described cholesterol in terms of "*good cholesterol*" and "*bad cholesterol*" and acknowledged the role of cholesterol on heart health.

Parental Distrust of Medications

Most parents expressed a strong preference for an initial trial of diet and exercise changes with medication use for hypertension or dyslipidemia as a "last resort." Some teens echoed parents' preferences for a trial of lifestyle changes first but more teens were accepting of medications. Some teens focused only on the mechanics of taking a pill daily. Parents and teens expressed similar reactions when asked about anti-hypertensive versus lipid-lowering medications.

Teen Focus on the Present

Developmentally, teens value the present and discount the future, which limits their motivation to act in the present to protect themselves from future CVD. This thinking could be seen in teens' understanding of CVD risk factors, in their reactions to potentially developing a CVD risk factor, and in their parents' descriptions of teen's priorities. When asked about hypertension, some teens focused on clinically unlikely symptoms for hypertension that would manifest immediately such as feeling "antsy", "very cranky", or experiencing "seizures" rather than future CVD risk. Teens also described present-focused strategies for managing CVD risk factors, describing hypertension and dyslipidemia as problems they would "fix" rather than as chronic health problems requiring ongoing management. In contrast, parents saw managing heart healthy risk factors as an ongoing perpetual process.

Strategies for Heart Health

Parents and teens agree on three strategies, "Family Support", "Exercise Partners", and "Specific and Realistic Guidance from Providers". Parents but not teens also endorsed the strategy "Exploit Providers Authority". While not explicitly acknowledged by parents or teens, the study team identified an additional provider strategy of "Emphasize Contributions of Both Genetics and Lifestyle." Related themes and quotes are described in Table 4. Among these strategies, the most commonly endorsed related to emphasizing the contributions of both genetics and lifestyle to CVD risk factors, particularly in parents, and desiring specific and realistic guidance from providers, particularly in teens.

Family Support

Many parents and some teens felt that making changes as a family was a useful strategy to encourage teenage healthy eating. Many parents felt their words and actions would have a strong influence on their teens' food choices. Parents, and some teens, believed that increased access to healthy food choices at home would enhance their teens' ability to eat healthily.

Exercise Partners

Teens and parents often mentioned that having family members or friends with whom to exercise or being on an athletic team would increase the likelihood of consistent exercise.

Specific and Realistic Guidance

Parents and teens requested that guidance from healthcare providers should be specific and realistic. Parents felt that specific recipes, specific exercises, and even a set menu for their teen would be helpful. Teens echoed these thoughts, wanting guidance on specific foods to eat and ways to fit exercise into their day.

Exploit Provider Authority

Many parents discussed that receiving heart healthy advice from a healthcare provider rather than a parent would encourage their teen to adopt heart healthy behaviors. While a couple of teens mentioned education from a nutritionist as helpful, teens generally did not mention that provider input would be motivating for heart healthy behavior. While parents may hope provider authority would motivate behavior change, parents seem to underestimate the influence of peers rather than authority figures in impacting teen behavior.

Emphasize Contribution of Both Genetics and Lifestyle

From the perspective of the study team, emphasizing both genetics and lifestyle factors contribute to hypertension and dyslipidemia might relieve teens of potential guilt or embarrassment on receiving a hypertension or dyslipidemia diagnosis and might help parents accept the need for medication intervention when indicated. Some teens stated they would respond to a new diagnosis of hypertension or dyslipidemia with feelings of guilt, embarrassment, or worry while other teens were able to rationalize the diagnosis based on their positive family history. Parents who understood that there is a genetic component to hypertension or dyslipidemia were more accepting of a possible need for medications.

Conclusions

In this qualitative study assessing teen and parent attitudes and beliefs regarding heart healthy behaviors in teens with T1D, several barriers to and strategies for heart healthy choices emerged. While some barriers such as the teens focus on the present may have been predictable based upon teens' development stage, other findings such as parental resistance to medication use are unexpected. Strategies that emerged, especially those endorsed by both teens and parents, are realistic and can help guide provider counseling (Supplemental Table 1).

Studies document suboptimal management of hypertension and dyslipidemia in youth with (5, 6) and without diabetes (9–11) suggesting a need for more effective management strategies. Interventional studies targeting heart healthy behaviors such as healthy eating and physical activity in teens (often with obesity) have met with mixed results (12–15). Behavioral interventions in pediatrics that are multimodal, extending beyond the clinic through email or mail outreach(16), or with participatory nutritional or exercise components(12, 15, 17) are most effective. Even these studies may have modest and/or inconsistent effects across CVD risk factors (14–16) or may not exhibit durability(16). In young adults, some social media based interventions have shown modest promise for preventing weight gain(18, 19) while another focused on weight loss showed limited efficacy and durability(20). Researchers might consider incorporating some of the strategies and addressing some of the barriers described here to improve the potency of their interventions.

Individual practitioners, who may not have access to multimodal participatory programs, often must develop effective counselling strategies to promote heart healthy behaviors in teens. Health care providers can apply the study's findings when engaging teens in conversations regarding heart health. Teen knowledge of hypertension and dyslipidemia is highly variable and often lacking so providers should consider assessing a teen's understanding and adjust their counseling accordingly. The teens' limited knowledge might not be overcome if providers direct their conversations to parents who possess a better understanding of CVD risk factors.

The effect of obesity-promoting environments on eating and exercise habits has been well-studied and documented (21) and commonly endorsed by study participants as major barriers to healthy behaviors. Resisting temptations coming from the environment, peers, and family members is especially difficult for teens who have poor impulse control at this developmental stage(22). Healthcare providers should consider evaluating which situations or persons make selecting heart healthy choices difficult for their teenage patients and then provide specific and realistic guidance aimed at selecting more healthy rather than unhealthy options in those situations. Providers may want to capitalize on the teens' focus on their current health rather than future risk by highlighting contemporaneous advantages of heart healthy lifestyle choices (e.g. weight loss, better energy, clearer skin) in addition to future CVD risk reduction. Teens with diabetes represent a unique population because of the demands imposed by diabetes management. When counseling teens with diabetes, providers should be sensitive to how the rigors of insulin management can impact teens' willingness to follow through on lifestyle recommendations.

Delays in medication initiation commonly occur in the management of hypertension and dyslipidemia in youth with (5, 6) and without diabetes (9, 23). This study suggests that parental preferences to avoid medications for hypertension and dyslipidemia could contribute to delayed medication initiation. Providers may want to avoid framing medication initiation as resulting from a failure of lifestyle change but as a useful adjunct while efforts at heart healthy behaviors continue. Further, emphasizing genetic as well as environmental contributions to hypertension and dyslipidemia when there is a positive family history of

these risk factors may help to alleviate teen and parental guilt and increase acceptance of medications.

This study has several limitations. First, there are limitations of generalizability. All participants received care at a single diabetes center and they were mostly white with well-educated parents. As this study was only among teens and parents of teens with T1D, results may not be fully applicable to teens without diabetes. We were not able to obtain the perspective of teens with T1D and hypertension because of a dearth of such diagnoses in our clinical population; such patients deserve further study. The interview format may have led to bias in participant responses if they sought to please or avoid judgement by the interviewer although interviewers were trained to remain neutral.

In summary, this study identified several strategies and barriers to heart healthy behaviors that can guide clinicians as they counsel and manage teens with elevated CVD risk factors. While the study participants consisted of teens with T1D and parents of teens with T1D who represent a distinct sample because of the substantial demands T1D places on teens and families, our study findings may be generalizable to other teens with dyslipidemia or hypertension in the absence of diabetes. Interventional studies incorporating the strategies and addressing the barriers described here may be useful to validate these approaches to CVD risk factor management.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Participant Characteristics

Teen Characteristics (N=22)	Mean±SD or %
Age (years)	17.4±1.7
Diabetes duration (years)	9.7±4.0
Sex (% Female)	68%
Race/ethnicity (% Non-Hispanic white)	82%
Educational Level	
Middle School	5%
High School	64%
College	32%
Family History of CVD/Hypertension/Dyslipidemia *	95%
% Teens with dyslipidemia (n)	45% (10)
A1c (without dyslipidemia) (%, mmol/mol)	8.3±1.0, 67±10.9
A1c (with dyslipidemia) (%, mmol/mol)	9.3±1.2, 78±13.1
LDL (without dyslipidemia) (mg/dl, mmol/l)	86±23, 2.2±0.6
LDL (with dyslipidemia, mg/dl, mmol/l)	145±54, 3.7±1.4
% of Teens with Dyslipidemia on Lipid-lowering Medications (n)	60% (6)
Parent Characteristics (N=25)	
Age range (%)	
41–50 years	54%
51–60 years	46%
Sex (% Female)	84%
Race/ethnicity (% Non-Hispanic white)	88%
Parents of teens with dyslipidemia (%)	40%
Parent education (%)	
High school	13%
Some college or technical college	25%
College or graduate degree	63%
Parent employment (%)	
Work full-time or part-time	72%
Stay-at-home parent	16%
Unable to work due to disability	12%
% of parents of teens with dyslipidemia on lipid- lowering medications (n)	60% (6)

All values are expressed as Mean±SD or %

* Family history includes 1st or 2nd degree relatives.

Table 2.

Perspectives on Barriers and Strategies for Cardiovascular Disease Risk Factor Management

Perspective	Barriers	Strategies
Parents and Teens	Pervasiveness of Unhealthy Options	Family Support for Teen Lifestyle Changes
Parents and Teens	Negative Influence of Peers and Family	Exercise Partners For Teens
Parents and Teens	-----	Specific and Realistic Guidance From Providers
Parents	-----	Exploit Provider Authority
Study Team	Parental Distrust of Medications	Emphasize Contribution of Both Genetics and Lifestyle
Study Team	Limited Teen Knowledge	-----
Study Team	Teen Focus on the Present	-----

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Table 3.

Themes and Supporting Quotes for Barriers to CVD Risk Factor Management

Pervasiveness of Unhealthy Options
<i>"It's really difficult in this world now cuz there's so much junk food out there..."</i> Mother of male without dyslipidemia
<i>"The fact that everyone around me usually eats junk food so it's always there."</i> 18 y.o. female with dyslipidemia
<i>"There's probably not gonna be a lotta healthy options because it's a school cafeteria....Some difficulties maybe trying to find something that's gonna be a good choice versus something that's a bad choice, especially when you're surrounded by obviously bad choices."</i> 18 year old male without dyslipidemia
Negative Influence of Peers and Families
<i>"I would say when she's out with her friends and they're driving around getting fast food and having a good time, that's probably where she's getting away from those recommendations."</i> Father of female without dyslipidemia
<i>"Going over to friends' houses. They always wanna eat junk food...I think it was very tempting to go over to their house a lot and eat their food."</i> 16 year old female without dyslipidemia
<i>"In my family, when you change your routine, and most people around you, your support, doesn't change their lifestyle, it's harder to keep up with that [change]."</i> 18 year old female with dyslipidemia
Parent Distrust of Medications
<i>"I would prefer she wouldn't have to. It would kind of bum me out, I guess if she had to take more medication or whatever. I would hope it would be something that she could have as a lifestyle. Have her lifestyle be so good that she didn't have high cholesterol."</i> Mother of female without dyslipidemia
<i>"It would just go into the pill box."</i> 19 year old male with dyslipidemia
Limited Teen Knowledge
<i>"High blood pressure, like cholesterol, can be very bad for your health. I honestly haven't heard much about it."</i> 16 year old girl without dyslipidemia
<i>"I know that high cholesterol isn't very good, but I don't really know anything else about it."</i> 15 year old female without dyslipidemia
<i>"...I know there's the good, the bad, and then there's triglycerides. The triglycerides is the fat in the blood. I think the LDL is the bad cholesterol. It clogs your arteries and can cause problems like heart attacks and strokes."</i> Mother of male without dyslipidemia
Teen Focus on the Present
<i>"He doesn't think about the consequences. There's nothing you can do. When you have a teenager, they do what they want to do."</i> Mother of male without dyslipidemia
<i>"I would make sure to listen to them[providers] and solve the problem as quickly as I can..."</i> 15 year old boy without dyslipidemia

Table 4.

Themes and Supporting Quotes for Strategies to CVD Risk Factor Management

Family Support for Teen Lifestyle Changes
<i>"Because I think that when families are involved, when families cook together, when they exercise together, those are the kinds of things that make things successful."</i> Mother of female with dyslipidemia
<i>"...me eating healthy makes her eat healthy."</i> Mother of female with dyslipidemia
<i>"I asked them [parents] to buy healthier snacks instead of chips or cookies or something like that. I asked them to get more fruits and I started eating fruit almost every day. More veggies, too."</i> 18 year old male with dyslipidemia
<i>"...I thought if my family could do it, then we could all do it together."</i> 16 year old female without dyslipidemia
Exercise Partners for Teens
<i>"If I had a gym buddy or someone to work out with me I'd definitely be more motivated to go and do more activities."</i> 18 year old female without dyslipidemia
<i>"If it's scheduled, they do it, and they participate in it, kind of like sports."</i> Mother of male with dyslipidemia
Specific and Realistic Guidance From Providers
<i>"[a nutritionist should] choose a manageable number of items that she should discontinue. I would say one or two."</i> Mother of female without dyslipidemia
<i>"[providers should provide] a very strict schedule, but with enough fluidity that I'd be able to apply it to my everyday life."</i> 15 year old male without dyslipidemia
Exploit Provider Authority
<i>"Because what her parents tell her, she doesn't hear that. Maybe if her providers told her that she needed to do more exercise that would be a good thing."</i> Father of female with dyslipidemia
Emphasize Contributions of Both Genetics and Lifestyle
<i>"not shocked cuz I knew that we had high cholesterol in our family, but I was more interested in, what could I do to prevent that or change that..."</i> 19 year old female with dyslipidemia
<i>"I would hope that we could [get cholesterol levels] better beforehand with the diet and exercise, but if, you know, it's like some things are hereditary. If you get it, you get it, and you have to take the medicine."</i> Mother of female without dyslipidemia
<i>"Well typically, I would say no [to medication], but knowing his family's history where his two grandparents have high cholesterol, even though they exercise a lot and eat very well, so I know part of its genetics."</i> Mother of male without dyslipidemia