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ETHNIC DIFFERENCES INFLUENCING THE IMPACT OF
CHILDHOOD TYPE 1 DIABETES MELLITUS IN LOW INCOME
FAMILIES

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by
Sadiqa Adero Ihsan Edmonds-Myles
2006

Abstract**ETHNIC DIFFERENCES INFLUENCING THE IMPACT OF CHILDHOOD TYPE 1 DIABETES MELLITUS IN LOW INCOME FAMILIES.**

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Over the past decade, great strides have been made in the treatment of type 1 diabetes mellitus. Although these advances have increased the proportion of young patients who are able to achieve strict metabolic control, there continues to be a disparity in the HbA1c levels of the African American and Hispanic American youth relative to Caucasian American youth, and in children of lower socioeconomic status (SES) relative to children of higher SES. Few studies have explored the underlying factors associated with this disparity and even fewer have analyzed how people of different ethnic backgrounds within lower socioeconomic groups deal with the diagnosis and its demands differently, particularly in the post-DCCT era of intensive diabetes management.

To enhance understanding of these factors, a qualitative study was carried out to describe factors which influence the impact of type 1 diabetes mellitus in people of different ethnic backgrounds within lower income socioeconomic groups. Seven patients of African American, Hispanic, and Caucasian heritage respectively who are treated by the diabetes treatment team at the Yale Pediatric Diabetes Program were recruited to participate in the study. Semi-structured interviews were conducted to explore each family's perception of challenges in caring for their child and maintaining control of their child's diabetes, parent-child relationships around management of diabetes, and responsibilities of parents with children who have been diagnosed with diabetes. We also

explored family support systems identified as being of assistance and aiding in minimizing the challenges in attaining successful diabetes treatment.

After thorough analysis of the data, there were multiple identifiable differences in how people of different ethnic groups manage and cope with diabetes. Most notable themes included a disparity in the emotional response of different ethnicities after diagnosis, differences in treatment modalities and reasons for their use across ethnicities, support systems identified, and clinician-patient relationships. Although these differences are likely multifactorial, with components of socioeconomic status, family structure, and family experiences involved, it is evident that ethnicity itself is an important factor. Therefore it is important for health care providers to consider the various issues which can affect the family's ability to manage and cope with diabetes, however it is also important for them to refrain from using race or ethnicity in a stereotypical way which might negatively affect their decision making and relationship with the patient.

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Introduction

Type 1 diabetes mellitus (T1DM) is a disease in which an autoimmune attack on the beta or islet cells of the pancreas causes hypoinsulinemia and resultant dependence on exogenous insulin for glycemic control. According to the National Institutes of Health, the prevalence of T1DM in the United States is approximately one in every 400 to 600. It is most prevalent in the Caucasian population, with Caucasians having an incidence which is 3 to 4 times higher than that of ethnic minorities, including African American and Hispanic American children (1). Although long-term vascular complications of diabetes remain the main source of morbidity and mortality from the disease, the Diabetes Control and Complications Trial (DCCT) demonstrated that these complications can be delayed or prevented by lowering plasma glucose and glycosylated hemoglobin (HbA1c) levels (2).

Great strides have been made in the treatment of T1DM, including increased intensity of diabetes management, introduction of insulin analogs and alternative methods of insulin administration, and better support and education for patients and caregivers of patients with T1DM (3). Although these factors have made metabolic control easier and decreased the incidence of early microvascular complications of diabetes, there continues to be a disparity in the African American and Hispanic American populations relative to the Caucasian American population (1), and in children of lower socioeconomic status (SES) relative to children of higher SES (4).

Several studies have shown that lower SES and minority race correlate with higher HbA1c levels, and often more hospitalizations for diabetic ketoacidosis, more long term complications, and increased age-adjusted mortality rates (1)(3). In a recent survey

of our own pediatric patient population, SES was found to be an important factor in metabolic control, with children of lower SES having the highest HbA1c values (5). Few studies have explored the underlying factors associated with this disparity or how diabetes impacts low income families of various ethnic backgrounds, particularly in the post-DCCT era of intensive diabetes management. The few which have examined these factors have been based on the results of questionnaire-based methods, therefore possibly missing important factors responsible for the ethnic and socioeconomic disparities that have been identified and the true impact of the disease on those affected. Further work is warranted to explore in greater depth, using qualitative methods, the underlying factors which make the role of ethnicity and SES important in the metabolic control and impact of T1DM, and possible solutions for bridging the gap.

Statement of Purpose

The overall purpose of the study is to examine ethnic differences in the impact of type 1 diabetes on lower income children of Caucasian, African American and Hispanic heritage. The two scientific aims of the study are to examine and compare:

1. Potential ethnic differences in parents' perceptions of obstacles and challenges in caring for the child and maintaining control of the child's diabetes, parent-child relationships around management of diabetes, and responsibilities of parents with children who have been diagnosed with diabetes.
2. Family support systems identified as being of assistance in managing and coping with diabetes, and aiding in minimizing the challenges in controlling their child's diabetes.

Methods

This was an exploratory descriptive study. To meet the aims, we selected approximately 7 patients of African American, Hispanic, and Caucasian heritage respectively who were treated by the diabetes treatment team at Yale Pediatric Diabetes Service. Patients were recruited who met the following criteria: age 10 – 18 years, diagnosis for ≥ 1 year, lack of comorbidities excluding controlled thyroid disease, and approximate socioeconomic status and race according to medical records. No compensation was offered to patients for their participation. The aim was to recruit families with low median household income ($< \$60,000$) using average income of block group (a division of zip code) because of a previous quantitative study of this patient population which showed a significant increase in HbA1c in families with a median income below \$60,000. (5). One higher income African American family with a median income of \$83,194 was recruited, however the data from this interview were only included in the case studies.

Semi-structured interviews (The interview guide may be found in Appendix A) were conducted using open-ended qualitative interviewing techniques to discuss perceived barriers to care, responsibilities, parent-child relationships outside of diabetes care and the effect of diabetes care on these relationships, and possible support systems for children with T1DM and their parents. The interviews were conducted with the parent and child separately followed by a short interview with them together to analyze better their relationship as it pertains to control of the child's diabetes. Open-ended descriptive questions of values and beliefs as well as questions about each family's experiences and challenges were used. The interviews were tape recorded and transcribed verbatim by a

professional transcriber. Transcripts were reviewed with the tape by the principal investigator to confirm accuracy.

A system of coding and categorizing the data was developed (Coding categories can be found in Appendix B) and used to code each interview. To confirm the reliability of coding, a second person coded the first four interviews in addition to the principal investigator, and the two met after each was coded to review the results. Those interviews along with the remaining interviews were then recoded by the principal investigator. After coding, themes which evolved in each interview were identified and compared across interviews to develop patterns across ethnicity. (6) The framework of the themes were analyzed within the context of four overall categories that evolved from the interview data, including Ability to Treat the Disease, Ability to Cope with Disease, View of Disease & Its Effect on Family, and Clinic Experiences. Atlas-ti, a qualitative analysis computer program, was used to assist in coding and sorting data.

Results

Forty patients were recruited, 28 agreed to participate, and interviews were ultimately completed with 22 families. The main reason for refusal to participate was the time required to participate (approximately 60 minutes). Because there are a small number of higher income minorities (with a median income of >\$60,000) who attend the Yale Diabetes Clinic, the study was focused on lower income socioeconomic groups. There were 7 families of Hispanic, Caucasian, and African American heritage respectively who participated. One multiethnic family was interviewed but not included in the analysis. One of the African American families was of higher income socioeconomic status (median income \$84,374) and therefore their data was not used in the demographic information listed below or in the analyses of overall trends.

The average income of the Caucasian American cohort was slightly higher than that of the Hispanic and African American cohorts, at \$45,991 in the Caucasian cohort and \$35,228 and \$37,662 respectively. The mean HbA1c of each group was similar when compared to the others, ranging from 7.3 to 7.6%. Average length of diagnosis was slightly lower in the Hispanic American cohort at 4 years, but approximately 6 years in the African American and Caucasian cohorts. All of the participants within the Caucasian cohort were being treated with the pump, whereas only one participant in the African American and two in the Hispanic American cohort were being treated with the pump at the time of the study. The African American patient within the higher socioeconomic group was also being treated with the pump at the time of the study. The demographics of participants are summarized in Tables 1 to 3 that follow.

Table 1: Demographics of Participants

| | African American (n=6) | Hispanic American (n=7) | Caucasian American (n=7) |
|--------------------------------------|---------------------------|----------------------------|-----------------------------|
| Female | 3 | 5 | 4 |
| Male | 3 | 2 | 3 |
| Age 10-12 | 2 | 2 | 2 |
| Age 13-15 | 2 | 3 | 2 |
| Age 16-18 | 2 | 2 | 3 |
| Avg income \pm SD | \$37,662 \pm \$9,935 | \$35,228 \pm \$10,479 | \$45,991 \pm \$11,632 |
| Mean HbA1c \pm SD | 7.6 \pm 1.8 | 7.3 \pm 1.3 | 7.4 \pm 1.0 |
| Number of pumps | 1 | 2 | 7 |
| Avg Duration of Diagnosis (years) | 6.3 \pm 3.1 | 4.0 \pm 3.7 | 6.1 \pm 3.5 |
| # Single Parent Households | 3 | 4 | 0 |
| # Two Parent Households | 4 | 3 | 7 |

Table 2: Demographics of Individual Participants

| Ethnicity | # | Age (Sex) | Median Income | HbA1c (Date) | Diabetes duration | Treatment method |
|------------------|----|-----------|------------------|----------------|----------------------|---------------------|
| African American | 2 | 12 M | 50,625 | 5.8 (3/15/05) | 2 years | Injection |
| African American | 4 | 12 F | 34,545 | 10.8 (2/23/05) | 10 years | Injection |
| African American | 5 | 13 M | 84,374 | 8.4 (3/23/05) | 8 years | Pump |
| African American | 7 | 17 M | 34,167 | 8.4 (4/5/05) | 7 years | Injection |
| African American | 8 | 13 F | 32,012 | 7.7 (3/22/05) | 8 years | Injection |
| African American | 12 | 16 M | 48,958 | 6.3 (5/16/05) | 6 years | Injection |
| African American | 15 | 15 F | 25,662 | 6.5 (6/27/05) | 6 years | Pump |
| Caucasian | 9 | 15 F | 41,295 | 5.7 (4/25/05) | 2 years | Pump |
| Caucasian | 10 | 16 M | 60,461 | 7.7 (5/4/05) | 7 years | Pump |
| Caucasian | 13 | 16 F | 49,500 | 8.3 (6/1/05) | 10 years | Pump |
| Caucasian | 17 | 17 F | 52,557 | 8.4 (7/27/05) | 10 years | Pump |
| Caucasian | 19 | 10 M | 52,212 | 7.0 (8/16/05) | 7 years | Pump |
| Caucasian | 20 | 15 M | 41,510 | 6.9 (8/15/05) | 6 years | Pump |
| Caucasian | 21 | 10 M | 24,401 | 8.0 (8/15/05) | 1 year | Pump |
| Hispanic | 1 | 14 F | 34,583 | 7.2 (3/8/05) | 12 years | Injection |
| Hispanic | 3 | 12 F | 19,044 | 9.4 (3/23/05) | 4 years | Injection |
| Hispanic | 6 | 15 M | 47,310 | 7.7 (4/5/05) | 1 year | Injection |
| Hispanic | 11 | 16 F | 41,250 | 7.3 (5/18/05) | 4 years | Pump |
| Hispanic | 16 | 11 M | 26,146 | 6.4 (7/27/05) | 1 year | Injection |
| Hispanic | 18 | 15 F | 32,012 | 5.3 (8/3/05) | 3 years | Injection |
| Hispanic | 22 | 14 M | 46,250 | 8.1 (7/27/05) | 3 years | Pump |

Table 3: Interview Information

| Interview Number | Parent Interviewed | Location of Interview |
|-------------------------|---------------------------|------------------------------|
| 1 | Mother | Home |
| 2 | Mother | Home |
| 3 | Stepfather | Home |
| 4 | Mother | Clinic |
| 5 | Mother | Home |
| 6 | Mother | Home |
| 7 | Mother | Home |
| 8 | Aunt (Guardian) | Home |
| 9 | Father | Home |
| 10 | Mother | Home |
| 11 | Mother | Home |
| 12 | Mother & Father | Home |
| 13 | Mother | Home |
| 14 | Mother | Home |
| 15 | Mother | Church |
| 16 | Mother | Home |
| 17 | Mother | Home |
| 18 | Mother | Home |
| 19 | Mother | Home |
| 20 | Mother | Home |
| 21 | Mother | Home |
| 22 | Father | Clinic |

Case studies were developed to provide a summary of the full stories of some of the families interviewed. These case studies gave a three dimensional view into the lives and emotions of families in response to living with diabetes. The selected interviews were chosen because they were representative of experiences which had been expressed by multiple families, however they demonstrate each family's unique reactions and methods of coping. The cases are grouped by ethnicity.

The themes which emerged across ethnic groups were compared and contrasted through tables (Appendix C) identifying the nature of the coded responses obtained as well as discussion about each. These are divided into four different categories, including View of Disease/Effect of Disease on Family, Ability to Treat Disease, Ability to Cope with Disease, and Clinic Experiences.

Case Studies

Case 1, Interview 2

12 y/o African American Male

Two parent household

HbA1c 5.8, Diagnosed 2 yrs

The mother talked about the anxiety she experienced when her son was initially diagnosed, but discussed at length how quickly he and the family had adjusted to the diagnosis. She even described the diagnosis as saving the family, saying “. . . he's the one who kind of saved the rest of us. . . so I said to him it is because of you that you saved us.” The child also seemed to recognize his gift to the family, saying “I am her special child” when asked about his relationship with his mother. Both identified having a good relationship with each other, Mom saying that she felt it was closer after his

diagnosis. Neither discussed spending time outside of routine management thinking about the diagnosis or its repercussions, although Mom discussed the anxiety she feels when he is playing sports and exerting himself more than she thinks he should. Mom also mentioned a sibling who had been diagnosed with autism shortly before this child's diagnosis, saying "So that one year I had to swallow and adjust to a lot of, I think too, because our minds are already open to learn about making his life as normal as possible." They both discussed cultural and school factors which they thought affected the ability of African Americans to cope with and treat diabetes. They identified the need for more education on diabetes in schools, especially predominantly African American schools, realizing the increase in incidence of type 2 diabetes in African Americans. They were able to identify an extensive support system for themselves, mostly consisting of family and friends.

Case 2, Interview 5

13 y/o African American Male, High SES

Two Parent Household

HbA1c 8.4 Diagnosed 8 yrs

The mother in this case identified frustration, satisfaction, and fulfillment as emotions she had experienced in response to the diagnosis and its responsibilities. When asked how it was fulfilling she responded, "Because I look at him as our hero. He has been through a lot no doubt, that I will never know. And I admire him for standing up and working through all he needs to do to stay in control. And in that sense, I feel fulfilled and I know that he is doing his best, and that's it." They both identified themselves as having a good

relationship that had not changed because he was so young when diagnosed. They reported positive experiences in dealing with the school and with various support groups and coping skills studies they had participated in before, but also noted feeling culturally/ethnically isolated with respect to the diagnosis at times. Mom noted, “I looked around at the seminar as an example, and I said I am the only parent here with a child and I saw an older man but that was really sad and I know there are other Black-African American diabetic children in this Yale community and I was very not happy not to see them.” She also suggested that an African American support group would help African American children with type 1 diabetes to bond. They were both able to identify friends and family as a significant support system.

Case 3, Interview 7

17 y/o African American Male

Single Parent Household

HbA1c 8.4 Diagnosed 7 years

This was a family which had been through a lot of emotional changes as a result of the child’s diagnosis. His mom spent the first several minutes of the interview discussing his diagnosis, which involved a misdiagnosis at his primary doctor’s office and a subsequent coma and ICU stay. Throughout the interview she referred to her mistrust of doctors after this incident, which seemed to set the framework for her future experience with diabetes and the health care field. She described a severe emotional response of depression, suicidality, and isolation in her son in response to his diagnosis, stating “Like

my sister, they used to come over all the time and they used to take him places, his grandmother used to call, on his father's side, used to call and she said sure come over and then she stopped. Kept on saying that she was busy, but I took it as being busy but he took it as being they didn't want to be bothered with him 'cause he had diabetes and something was wrong with him." However she also described his adjustment over the years, and how she is a better parent now because of his diagnosis. The child now views his disease as "fun" because it has allowed him to meet new people and he no longer feels it is limiting to him. Mom expressed her desire for him to be on the pump, which she thinks will be easier for him, but has been told that his HbA1c was too high at the time. Mom also identified issues with job security and transportation with a child with a chronic illness, saying how lucky she felt to have an understanding employer who allowed her to keep her job despite missing days because of her son's illness. She also described multiple struggles with her son's school, resulting in her eventually having to place him in a different school so that she could monitor him more closely herself. They identified their support systems as family, teachers, classmates, and a diabetes support group in the past.

Case 4, Interview 3

12 y/o Hispanic Female

Two Parent Household

HbA1c 9.4 Diagnosed 4 years

This interview revealed how significantly other family members could be affected by the diagnosis. The stepfather noted an array of emotions in response to the diagnosis,

including frustration, fear, anxiety, guilt, and resentment. Many of the feelings were in response to the behavior of the child's mother, whom both the father and child identified as being distant and uninvolved in the management of diabetes or support of the child. She mentioned at one point that “. . . she (my mom) hates that I have it (diabetes)”. She also discussed the isolation she felt at school when other children were allowed to eat foods and do things that she was restricted from doing. When asked what would make it easier, her response was “I want it to just go away”. She and her stepfather seemed to have a good relationship, however her regression in response to the diagnosis and her tumultuous relationship with her mother seemed to have strained the relationship. Her stepfather had a support system which consisted of two friends, however the child's support system consisted of professionals and very few friends (nurse, school social worker, principal, and father's friend who is a therapist). They identified a resolution of family issues as the only thing which could make coping easier for them. In the child's words, “(I will feel better about it) if my Mom was talking to me more.”

Case 5, Interview 6

15y/o Hispanic Male

Single Parent Household

HbA1c 7.7 Diagnosed 1 year

The overarching theme of this interview was the amount of anxiety the mother felt in response to her son's diagnosis and management. She talked about always being worried about him, whether she would be able to wake him up each morning, or if he was okay at school. She also described her son's initial anger and sadness about the diagnosis, and

her difficulty in making sure he took his insulin and followed the rest of his management routine. Her son's advice on how he has dealt with the diagnosis was, "Don't think of it as a disease 'cause it's not, just like a condition, like you can't eat that much sugar and there's a lot of other stuff you can eat, you don't have to (think) about it all the time." They described a good relationship which became more loving after he was diagnosed. When asked the easiest part, the mother replied that there were no easy parts. She identified financial pressures as a single mother that forced her family to share a house with another family, and share a bedroom between them. She expressed that more education would help her to get a better job, and decreased financial pressure and better housing would help her son to cope with diabetes. She also discussed the pain and stress of immigrating, saying "When he got here he started with diabetes, he left Brazil, he got here living only with his father, not knowing when I was going to be able to come so that was when he got diabetes. I feel like should I have kept (him) at home in Brazil, did I do the right thing in letting him come. Maybe he would have got the diabetes any way but I will never know." She could identify no support system for herself and her family because of most of her close family still living in Brazil, and stated that at times she wishes she could go back to Brazil and wonders if life would have been easier for them there.

Case 6, Interview 22

14 y/o Hispanic Male

Two Parent Household

HbA1c 8.1 Diagnosed 3 years

This was one of the few interviews done with a father, and was interesting because as he talked it became apparent that the father also had type 1 diabetes, a fact which was previously unknown to me. In response to the first interview question on what it is like to have a child with diabetes, he discussed his childhood with diabetes, saying “It’s hard because, there was three, another brother and my sister, and sometimes they would eat sweets and I couldn’t and you know, the adjustments that you have to make, having lows and highs, and not feeling good, and everybody would be playing and running around and doing things and some of the things I couldn’t do. That was the hardest part about it.” He described having support from his wife in his son’s diabetes care, but described that it was easier for him as he knew what to do. The son described the love and appreciation he had for his father for caring for him so well – a job which he admitted he did not do very well independently, stating “I am the irresponsible one. I am the one who never checks his sugar, but then when they (my parents) get me, oh did you check your sugar, then I go okay and I check it, and they get me most of the time so usually I forget, they get me, I check it like around three times a day.” His father described God as their support system, saying “God. God is my support. I have a lot of faith and trust in God and because of God I am dealing with it and I have no problem with it ‘cause the bottom line is I am in His hand and whatever happens, He knows what to do.”

Case 7, Interview 9

15 y/o Caucasian Female

Two Parent Household

HbA1c 5.7 Diagnosed 2 years

This family had an almost nonchalant way about their experience with diabetes and its management. They seemed to attribute this to the fact that they knew exactly what the diagnosis was and how to treat it. They had an experience in which the child dealt with a rare skin disorder which took an extended period for them to obtain a diagnosis, and expressed relief in how definitive the diabetes diagnosis was. The father described fear and guilt as his initial emotional responses to the diagnosis and management, but as he adjusted it became “part of life” and “no extra stress”. They identified church and friends as support systems for them, and could not identify anything that would make treating or coping with diabetes easier (other than a cure).

Case 8, Interview 10

16 y/o Caucasian Male

Two Parent Household

HbA1c 7.7 Diagnosed 7 years

This family seemed very well adjusted to diabetes based on the practical nature in which they were able to discuss its impact on their lives. The mother discussed anxiety and hypervigilance being her major responses to the diagnosis, but said that it really “was not that bad”. When discussing the daily responsibilities, she said, “I’ve heard other people be so dramatic about it but that doesn’t seem to concern me too much, the day to day. It’s not too bad.” The child talked about caring about his future being the impetus behind the higher demands he places on himself for his diabetes control. Specifically he said, “I have a very active lifestyle. I snowboard, I weightboard, I ski, I sail, basketball, tennis, soccer, I run any time I can . . . My great aunt needed her leg amputated because of

diabetes. I can't play soccer too great with one leg so I just want to keep my body in condition where I can do the things I do now for my entire life if possible." His Mom expressed concern about whether he would be limited in job choices or discriminated against because of his diagnosis, however said that those were her worries and he had not expressed similar ones. When asked about their support systems, his Mom named his school and the Yale Diabetes Clinic. She mentioned that there was no one in the community, but said they didn't feel lonely as a result.

Case 9, Interview 19

10 y/o Caucasian Male

Two Parent Household

HbA1c 7.0 Diagnosed 7 years

This family was able to initially discuss the diagnosis and its management in a very objective way, however upon conversing further with them on their experiences it was obvious how emotional and painful the disease, the responsibilities that go along with it, and the experiences with health care practitioners surrounding the diagnosis were for them. The mother identified an array of emotions in response to the diagnosis and its management, including depression, disappointment, frustration, and hatred. She discussed how profoundly the diagnosis changed her parenting strategies, feeling that some of her responsibilities in managing her son's diabetes were directly opposed to her vision of herself as a mother. To this effect she stated, "One of the few things I thought I knew with absolute certainty going into parenthood was that I would never intentionally hurt my child which is just one of the great jokes of the universe. When I walked into that

hospital, actually you are going to be poking your child how many times a day. And I was also, eat when you feel hungry, I wasn't really into routines at that point and diabetes has completely transformed our family life. Not in ways that have always been bad, I've come to really understand the power for all of us having routines and that's actually been very useful with our second kid." They both talked about the profound anxiety and stress that accompanied each clinic visit, and described various ways in which it was frustrating for them. Mom was able to identify various sources of support, including family, the child's school, other studies, the Yale Diabetes Clinic, and various books and websites.

Across-Case Analysis

View of Disease/Effect of Disease on Family

Table 4: Emotional Response to Diabetes

| Hispanic | Emotional Response of Parent to T1DM | Parent's Perception of Child's Emotional Response | Emotional Response of Child to T1DM |
|------------------|--|--|--|
| 1 | Awful, depression | "Wanted to die", isolation, discomfort | Frustration |
| 3 | Traumatized, challenged, fear, anxiety, guilt, resentment, frustration | Resentment, hate, needy | "Want it to go away", anger, isolation |
| 6 | Anxiety | Depression, anger | X |
| 11 | Fear, anger, fatigue, stress, anxiety, embarrassment | Brave | X |
| 16 | Anxiety | Anxiety, isolation, why me? | Fear, isolation |
| 18 | Fear, anxiety | Fear, why me?, acceptance | Bothersome |
| 22 | Difficulty | Depression, acceptance | Annoying |
| | | | |
| African American | Emotional Response of Parent to T1DM | Parent's Perception of Child's Emotional Response | Emotional Response of Child to T1DM |
| 2 | Anxiety, "wreck", adjustment | Why me?, acceptance | No adjustment |
| 4 | Why? Fear | Isolation, why me? | Isolation |
| 7 | Stress | Anger, suicidal, felt like a burden/disliked, mortality inevitable | Embarrassment, acceptance |
| 8 | Anxiety | Good, minimal response | Anger, fun |
| 12 | X | Frustration, acceptance | Aggravation |
| 15 | Not end of world | No response | Fun |
| | | | |
| Caucasian | Emotional Response of Parent to T1DM | Parent's Perception of Child's Emotional Response | Emotional Response of Child to T1DM |
| 9 | Fear, adaptation, guilt | Anxiety, courage | Painful, why me? |
| 10 | Anxiety, hypervigilance | Afraid of death, challenged, acceptance | X |
| 13 | Anxiety, fatigue, hypervigilance, isolation | Minimal response | Fine |
| 17 | Hypervigilance, anxiety | Minimal response | X |
| 19 | Hatred, sadness, frustration, disappointment, stress, depression | Why me?, depression, conscientious | Stressful, overwhelming, why me? |
| 20 | Fear | No tears, calm | X |
| 21 | Anxiety | Anger, pride | Fun |

Table 4 summarizes emotional responses to disease, which were similar in many ways across ethnic groups. Families described emotional responses of anxiety, fear, and stress most commonly. Most families discussed the increased responsibility and hypervigilance necessary with diabetes, but many talked about it being “not so bad” as they adjusted to the diagnosis and its management. When asked what it is like to have diabetes, one child replied, “. . . you wish you could do what everybody else is doing but you can’t cause you have a big change and sometimes nobody understands what you are going through . . .” The father of one child commented, “Now it’s a real, it’s an everyday experience, we’ve learned to live with it. In the beginning it was very tough and very frightening. I remember the night she got it I stayed up till three or four in the morning doing research on the Internet. But now it’s like I said, it’s just part of life.”

Table 5: Parent's General View of Diabetes

| Hisp | Parent's General View of T1DM | Parent's View of Easy | Parent's View of Hard |
|-------|--|-----------------------|--|
| 1 | Importance of child's responsibility, self sufficiency; Hard work 150% | Self sufficient child | Teenage rebellion |
| 3 | X | Nothing | Emotional response of child |
| 6 | X | Nothing | Anxiety of the unknown |
| 11 | Inc responsibility, selflessness | Pump | Anxiety about night, finding a balance |
| 16 | Hard | Nothing | Child adherence |
| 18 | Not that hard; scary in past | Self sufficient child | Managing routine |
| 22 | Inc responsibility | Pump | Child adherence |
| | | | |
| Af Am | Parent's General View of T1DM | Easy | Hard |
| 2 | Normal; saved the family | Self-sufficient child | Anxiety |
| 4 | X | Nothing | Anxiety of unknown |
| 7 | Inc work; changed parent for better; need for parent-child partnership | Relationship | Hypervigilance |
| 8 | Not bad | Self-sufficient child | Child adherence |
| 12 | Big change, not difficult, routine | Familiarity c routine | Managing numbers in atypical situations |
| 15 | Inc focus on child | Pump | Child adherence |
| | | | |
| Cauc | Parent's General View of T1DM | Easy | Hard |
| 9 | Part of life, no extra stress | Self-sufficient child | Remembering to be hypervigilant |
| 10 | Not that bad | Ordering supplies | Emotional response to nonadherence of child |
| 13 | Isolating, brings family together, increased organization | X | Being away from child |
| 17 | Challenging | If child is adherent | Teenage rebellion |
| 19 | Stressful | Food choices | Anxiety of unknown, emotional response of both of DM regimen |
| 20 | Not so bad | Pump, food choices | Emotional response of child |
| 21 | Routine | Daily routine | Emotional response of child |

Table 6: Child's General View of Diabetes

| Hispanic | Child's General View of T1DM | Child's View of Easy | Child's View of Hard |
|------------------|--|---------------------------------------|--|
| 1 | X | X | Managing blood sugar |
| 3 | X | Self sufficiency | Restrictions in school; routine |
| 6 | Inc responsibility; not disease, just condition | Nothing | Managing blood sugar |
| 11 | Normal; Self responsibility & partnership with parents important; No reason to feel ashamed | Nothing | Routine; Inc responsibility |
| 16 | Hard, challenging | Knowing routine & limitations | Administering shots |
| 18 | Weird, different | Eating, everything | Routine |
| 22 | Hard | Pump | Adherence to diet |
| | | | |
| African American | Child's General View of T1DM | Easy | Hard |
| 2 | Regular; makes me special | Everything | Writing blood sugar |
| 4 | Boring, unfair | X | Managing blood sugar |
| 7 | Fun sometimes; allows me to meet new people; not limiting (i.e. in sports); must learn to be self sufficient | Excuse to eat well | Checking blood sugar, giving shots, sports |
| 8 | Fun sometimes; makes me mad sometimes | X | Adherence to diet |
| 12 | Extra work | Checking blood sugar | Adherence to diet |
| 15 | Fun, frustrating | Checking blood sugar & bolusing; pump | Adherence to diet |
| | | | |
| Caucasian | Child's General View of T1DM | Easy | Hard |
| 9 | Hard & easy; a pain | Everything | Managing blood sugar |
| 10 | Care about future, so put higher demands for control on myself | Technology | Atypical schedule |
| 13 | Normal | Pump | Managing blood sugar |
| 17 | "Just a disease I've got to live with" | Administering insulin | Managing blood sugar |
| 19 | X | Routine | Wondering why me? |
| 20 | Annoying | Counting carbs | Checking blood sugar |
| 21 | Painful, fun, annoying | Changing cartridge | Inserting site |

As demonstrated in tables 5 and 6, which summarize the difficulty and respective ease of the dealing with the diagnosis, families identified a variety of responses. The responses for what is easy included the child being self-sufficient, familiarity with routine, and the pump as mode of insulin administration. Striking was the fact that

nothing of ease was identified in the Hispanic cohort, in which three parents and two children could not identify anything easy about diabetes management. One parent stated, “I don’t think any of it has been easy because just the thought of her being ill is not good for me. Nothing really has been good. I am constantly worrying about her. . .” One mother in the Hispanic cohort said, “But the worst time was in the beginning. When you are used to it, it’s a new life. Because the people who start with diabetes, everything changed, when she’s a baby, I carried the glucagons, the machine, the insulin, the tablets, juice, you know, everything, what happened if she’s high, I’ve got to manage, if she’s low, I’ve got to manage so for me in the beginning, was awful to put her new life in my schedule. . .” This sentiment was expressed only once in the African American cohort and not said at all in the Caucasian cohort.

Table 7: Relationships

| Hisp | Parent-Child Relationship | How it Changed | Child-Parent Relationship | How it Changed |
|-------|---------------------------------|--|----------------------------|----------------------------|
| 1 | Good | More love | Good | Early dx |
| 3 | Good | Regression of child | Good c Dad, Bad c Mom | More attention from parent |
| 6 | Good | Teenage rebellion; inc difficulty | Good | No change |
| 11 | x | Closer | Normal, OK | No change |
| 16 | Good, could improve | No change | Good | More strict |
| 18 | Good | Closer | Close | More anxiety from parent |
| 22 | Great | Closer | Good | More concern from parent |
| | | | | |
| Af Am | Parent-Child Relationship | How it Changed | Child-Parent Relationship | How it Changed |
| 2 | Very nice | Closer | Good | No change |
| 4 | Good, close | No change | Okay | No change |
| 7 | Ups & downs, overprotective | Closer | Good | Closer |
| 8 | Good | X | Good | Closer b/c custody change |
| 12 | Good | No change | Good | No change |
| 15 | Great | No change | Good | Closer |
| | | | | |
| Cauc | Parent-Child Relationship | How it Changed | Child-Parent Relationship | How it Changed |
| 9 | Close | No change | Wonderful | No change |
| 10 | Good | Stronger | X | x |
| 13 | Good | Early dx | Good | Early dx |
| 17 | Rocky secondary to anger issues | Early dx | Bad before, getting better | No change |
| 19 | Very close | Parent c more authoritarian role | Good | Early dx |
| 20 | Good | Parent's c bigger role in child's life | Okay | Early dx |
| 21 | Close | No change | Close | Closer |

As displayed in Table 7, there were no differences between the groups in parent-child relationships and how they changed in response to the diagnosis. Many parents identified no change at all, and some identified a closer or stronger relationship after the diagnosis. There were also no differences between the groups when children were asked about their relationships with their parents, however there was a notable difference in how the

relationship changed according to the child. Most children noted no change or a closer relationship after the diagnosis, however in the Hispanic cohort there were three responses about the increase in anxiety, concern, or attention from the parent after the diagnosis.

Table 8: Preoccupation with Disease

| Hisp | Parent's Preoccupation | Inferred Preoccupation with Disease | Child's Preoccupation | Child's Perception of Parent's Emotional Response |
|-------|------------------------|---|-----------------------|---|
| 1 | 80-90% time | X | with routine | X |
| 3 | Minimal | Always | with routine | Stressful, hatred, doesn't care |
| 6 | Always | Always | none | X |
| 11 | Always | Always | with routine | X |
| 16 | Always | X | always | X |
| 18 | With routine | X | with routine | More worry |
| 22 | Always | X | with routine | More concern |
| | | | | |
| Af Am | Parent's Preoccupation | Inferred Preoccupation with Disease | Child's Preoccupation | Child's Perception of Parent's Emotional Response |
| 2 | None | With sports | with routine | X |
| 4 | Minimal | X | depends on BS | X |
| 7 | A lot | X | always | X |
| 8 | A lot | X | with routine | X |
| 12 | Always | X | minimal | X |
| 15 | With routine | X | with routine | Fear of death |
| | | | | |
| Cauc | Parent's Preoccupation | Inferred Preoccupation with Disease | Child's Preoccupation | Child's Perception of Parent's Emotional Response |
| 9 | None | x | with routine | X |
| 10 | With routine | Randomly worry about future | depends on BS | X |
| 13 | Depends on blood sugar | Randomly worry about future & social impact | with routine | X |
| 17 | Depends on blood sugar | x | minimal | X |
| 19 | Always | Middle of night uncertainty | with routine | X |
| 20 | With routine | x | minimal | X |
| 21 | With routine | Randomly worry about future | a lot | X |

Table 8 summarizes the preoccupation of families on diabetes and its management. Parental preoccupation appeared to be different across ethnicities. There were a variety of responses to this question, including parents who felt they spent all of their time thinking about diabetes, time just needed to complete the routine of diabetes management, and minimal or no time thinking about it. However in the Hispanic cohort again there were five parents who felt they spent all of their time thinking about diabetes, and one additional parent who felt she spent 80 – 90% of her time thinking about diabetes.

In the African American cohort, there was one parent who identified that she thought about diabetes all of her time, and two who felt they spent a lot of time focused on diabetes. This is in contrast to the Caucasian cohort, in which only one parent identified spending more time thinking about diabetes than needed to complete the routine of diabetes management. One mother stated, “We’ve been doing it so long now that it’s not the overwhelming focus of everyday, which it was for at least the first year. . . . It’s sort of a stressor that never goes away, an extra piece of anxiety that never goes away.”

Ability to Treat DiseaseTable 9: Division of Responsibility

| Hispanic | Parent's Responsibility | Child's Responsibility |
|------------------|-------------------------|------------------------|
| 1 | Equal | Equal |
| 3 | Parent | Parent |
| 6 | Child | Child |
| 11 | Child | Child |
| 16 | Equal | Equal |
| 18 | Child | Child |
| 22 | Child | Parent |
| | | |
| African American | | |
| 2 | Child | Child |
| 4 | Child | Child |
| 7 | Varies | Child |
| 8 | Child | Child |
| 12 | Equal | Child |
| 15 | Equal | Child |
| | | |
| Caucasian | | |
| 9 | Child | Child |
| 10 | Child | Child |
| 13 | Child | Child |
| 17 | Parent | Parent |
| 19 | Equal | Equal |
| 20 | Child | Child |
| 21 | Child | Child |

Table 10: Ease of Treatment

| Hispanic | What Has Made Treatment Easier for Parent | What Would Make Treatment Easier for Parent | What Has Made Treatment Easier for Child | What Would Make Treatment Easier for Child |
|-------------------------|---|---|--|--|
| 1 | Accessibility of PMD | new technology | X | inc guidance |
| 3 | X | X | Staying c routine | x |
| 6 | X | stem cells/cure | X | new technology |
| 11 | Pump | financial stability, more pump training & education | X | exercising, increased public awareness |
| 16 | X | pump, adherence of child | X | cure |
| 18 | books, carb counting | cure, in house nutritionist | X | pump |
| 22 | X | new technology | pump | new technology |
| | | | | |
| African American | | | | |
| 2 | X | Pump | X | nothing |
| 4 | Accessibility of Yale | X | Praying | Not sure, praying |
| 7 | X | X | X | Good DM care |
| 8 | Pump | cure, new technology | Pump | Not sure |
| 12 | X | new pump, better insurance | X | Nothing |
| 15 | Pump | | X | New technology |
| | | | | |
| Caucasian | | Cure | | |
| 9 | Pump | new technology | pump | cure |
| 10 | Pump | cure, new technology | new technology, pump | New technology |
| 13 | pump, better glucometer | Nothing | pump | Not sure, cure |
| 17 | X | new technology; clinic improvement | insulin | Cure |
| 19 | X | cure, new technology | X | New technology |
| 20 | Pump | Nothing | X | New technology |
| 21 | X | | X | Cure, new technology |

As seen in Table 9, the division of parent-child responsibility was similar across groups, with most families identifying the child as most responsible for diabetes management. However, in the Hispanic cohort children more often identified equal responsibility or the parent as the primary person responsible for diabetes management. Table 10 summarizes

responses to what has made or would make managing diabetes easier. Most families identified a cure as ideal and new technology a second best.

Table 11: Parental Identification of Factors

| Hispanic | Financial Factors | Family Factors | School Factors | Cultural Factors |
|------------------|---|----------------------------------|-------------------------|---|
| 1 | X | Single mom | X | Language |
| 3 | X | Uninvolved mother | X | X |
| 6 | Needs better job; house (3 fam members share same BR) | Single mom, uninvolved father | X | Immigration - isolation from family in US, different food preferences |
| 11 | Healthy food is expensive, needs better job, good insurance | X | X | Immigration - isolation from family |
| 16 | Job - working at night | Single mom | X | X |
| 18 | Multiple jobs to be financially stable | Single mom | X | X |
| 22 | Both parents work | X | X | X |
| | | | | |
| African American | Financial Factors | Family Factors | School Factors | Cultural Factors |
| 2 | X | X | Neg - lack of education | Old fashioned mindset/lack of education and understanding in AfAm community |
| 4 | X | Young mom | X | X |
| 7 | Unstable job security, transportation | Family fear of treating diabetes | Neg before, pos now | Question of racism |
| 8 | X | X | Pos | X |
| 12 | X | X | X | X |
| 15 | Expense of meds, poor insurance | X | X | X |
| | | | | |
| Caucasian | Financial Factors | Family Factors | School Factors | Cultural Factors |
| 9 | X | X | X | X |
| 10 | X | X | Pos | X |
| 13 | X | X | X | X |
| 17 | X | X | X | X |
| 19 | X | X | Neg | X |
| 20 | X | Unhelpful family support | X | X |
| 21 | X | X | X | X |

Table 12: Child Identification of Factors

| Hispanic | Child - Family Factors | Child - School Factors | Child - Cultural Factors |
|------------------|---------------------------------------|-------------------------|----------------------------|
| 1 | X | X | x |
| 3 | Uninvolved mother, rocky relationship | Neg | Food preferences, language |
| 6 | X | X | x |
| 11 | X | Neg | x |
| 16 | X | X | x |
| 18 | X | X | x |
| 22 | X | X | x |
| | | | |
| African American | Child - Family Factors | Child - School Factors | Child - Cultural Factors |
| 2 | X | Neg - lack of education | |
| 4 | X | X | x |
| 7 | X | Neg | x |
| 8 | X | X | x |
| 12 | X | X | x |
| 15 | X | X | x |
| | | | |
| Caucasian | Child - Family Factors | Child - School Factors | Child - Cultural Factors |
| 9 | X | X | x |
| 10 | X | X | x |
| 13 | X | X | x |
| 17 | X | X | x |
| 19 | X | X | x |
| 20 | X | X | x |
| 21 | X | X | x |

Tables 11 and 12 summarize factors which families expressed affected their ability to manage and cope with diabetes. Financial factors were disparately distributed across groups, being identified as important only in the Hispanic and African American cohorts. Both cohorts identified issues with job security, benefits, and income, as well as the expense of medicines and healthy foods. Insurance quality was also identified as an issue which could impede them from obtaining the best treatment for their child. In discussing financial pressures in dealing with diabetes management, one mother

commented, “I was just concerned that when you’re not in that bracket range, of money, financially, you still got to worry cause there are so many foods that you need to have in the house, and sometimes the money isn’t there . . .”

Family factors were also disparately distributed, being discussed in the African American and Hispanic cohorts more frequently. The issue of a single or uninvolved parent was discussed in four different cases within the Hispanic cohort. One of the mothers within the Hispanic cohort said, “It’s very hard for me ‘cause I have a daughter, too, and I’m a single mother so it’s really hard but I think about (my son) the whole day. Sometimes my daughter feels jealous because she thinks that I don’t care about her, that I cook only for (my son). . .” Lack of family support and young parents were two issues discussed in families in the African American cohort. One family within the Caucasian cohort discussed unhelpful family support, in which family offered lots of support but in unhelpful ways.

There were a variety of factors associated with the school discussed across all groups, some positive experiences and some negative. Although in general more negative experiences than positive were discussed, they did not seem to affect the cohorts differently. On the other hand, cultural factors were identified disproportionately in the Hispanic and African American cohorts. The Hispanic cohort identified language barriers, cultural isolation, and different food preferences as being cultural barriers to their ability to treat diabetes. When discussing a hypoglycemic event which occurred after she changed the family’s meal time on the recommendation of a clinician, one Hispanic mother remarked, “Cause (my son) is used to coming home from school and having another lunch at home cause we come from another country so we’re not used to

eating sandwiches and this kind of food the whole day. We need to have at least one meal like rice and beans. . .”

The African American cohort also identified cultural isolation as well as a lack of education on diabetes in the African American community. One mother noted, “When we were in the hospital I noticed that, there was one side where there were kids that were already diagnosed that were having some problems, all that one side was all minorities. The newly diagnosed parents on our sides were all white and the moms and dads stayed in that room with that kid non-stop. Just seemed like the trauma, where these kids were actually running into complications and the other side that we were on was quiet. You know what I mean, so I noticed right away, from day one, the first day he was admitted there was a difference, right then and there.”

Ability to Cope With DiseaseTable 13: Support Systems Identified

| Hispanic | Parent's Support System | Parent's Perception of Child's Support System | Child's Support System |
|------------------|---|---|------------------------|
| 1 | Husband in past, now nobody | X | X |
| 3 | Friend, ex-coworker | father's friend, nurse, school social worker, principal | X |
| 6 | None | X | X |
| 11 | Friends, co-workers, husband, kids | X | Friends |
| 16 | None | X | X |
| 18 | Child, Friend | X | X |
| 22 | God | X | x |
| | | | |
| African American | Parent's Support System | Parent's Perception of Child's Support System | Child's Support System |
| 2 | Husband, friends, family | Grandfather, friend with DM, stepfather, book | friend with T2DM |
| 4 | Child's father, family | Friends with DM | friend with DM |
| 7 | Family | Teachers, classmates, diabetic support group, sister | Friends |
| 8 | None, husband, child's father, family, friend | X | X |
| 12 | None, religion | X | X |
| 15 | God, family | God | X |
| | | | |
| Caucasian | Parent's Support System | Parent's Perception of Child's Support System | Child's Support System |
| 9 | Church, friends | x | X |
| 10 | Yale, nobody in community but okay with that, school | Friends | X |
| 13 | Nobody for psych support, friend, husband, daughter, Yale | x | X |
| 17 | Family, Yale | x | X |
| 19 | Friend, Yale, sister, child's teacher/school, books, websites | x | X |
| 20 | Husband, family | Aunt, friends | X |
| 21 | Yale | Friends in past, none now after move | Mom |

Ability to cope with disease includes support systems, methods used for coping, and various other factors. Parent's identified a variety of support systems which they felt

were available to them, most often named were family and friends (Table 13). However there was a distinct difference between the ethnic groups. Both the Hispanic and African American cohorts included parents which could not identify any form of support. This is in contrast to the Caucasian cohort, in which every family was able to identify some form of support. One of the mothers from the African American cohort was able to identify an extensive support system for herself and her child, saying “. . . friends and family have lifted the burden for me ‘cause instantly my brothers and sisters, cousins became diabetic specialists so now it’s kind of like the village that raised the kid.” The other striking difference between the Hispanic and African American cohorts and the Caucasian cohort was that Yale was mentioned as a support system four times within the Caucasian group, however was not mentioned within the African American and Hispanic cohorts.

One similarity between the groups was that there were a few instances in which God or religion was named as a support system. When asked about her support system, one of the African American mothers stated, “God. He is our support group. Somebody said to me how do you make it. I just say well you’ve got to read Habakkuk 2:4. You shall live by faith. We live by faith because when she was diagnosed I didn’t know where her medication was coming from, anything, and then we met (the social worker) and it just worked itself out.”

Table 14: Coping Mechanisms

| Hispanic | Would Make Coping Easier for Parents | Has Made Coping Easier for Parents | Would Make Coping Easier for Child | Has Made Coping Easier for Child | Method for Coping |
|------------------|--|--|---|---------------------------------------|--|
| 1 | Support group | Accessibility of PMD, pump | kid support groups | x | Humor |
| 3 | resolution of family issues | X | better family dynamics | clinic, D/C of pump | X |
| 6 | financial stability, better housing | X | x | x | Normalization |
| 11 | X | Pump | kid support groups | x | Humor |
| 16 | Support group | X | x | x | X |
| 18 | X | X | x | x | Normalization |
| 22 | X | X | x | x | Faith in God |
| | | | | | |
| African American | What Would Make Coping Easier for Parents | What Has Made Coping Easier for Parents | What Would Make Coping Easier for Child | What Has Made Coping Easier for Child | Method for Coping |
| 2 | Cure | X | x | x | Normalization, humor, child "saved" family |
| 4 | Support group | Accessibility of Yale | x | x | Bright side; normalization; keeping child active |
| 7 | adult daycare for sick days | school program | x | x | X |
| 8 | X | X | kid support groups | x | Normalization, bright side, religion |
| 12 | X | X | x | x | Spirituality, religion |
| 15 | X | X | | | |
| Caucasian | What Would Make Coping Easier for Parents | What Has Made Coping Easier for Parents | What Would Make Coping Easier for Child | What Has Made Coping Easier for Child | Method for Coping |
| 9 | X | X | x | x | Normalization |
| 10 | X | family is closer | X | x | Active lifestyle |
| 13 | control of child's habits, increased family support and friend with DM for child | X | X | x | Bright side |
| 17 | X | X | X | x | X |
| 19 | X | other studies, psychologist with one study | X | x | X |

| | | | | | |
|----|--|------|---|---|--------------------|
| 20 | better mode of communication for child | X | X | x | X |
| 21 | X | Yale | x | x | DM is child's gift |

When asked what would make coping easier (Table 14), the answers also split between the African American and Hispanic cohorts, and the Caucasian cohort. Support groups were mentioned both by parents and children in the African American and Hispanic cohorts, whereas this was not mentioned in the Caucasian cohort.

Method for coping was examined based on information families gave about how they dealt with the diagnosis of diabetes and its management. There were a variety of methods used by families, including normalization, humor, religion, reasoning about what “could be worse”, and viewing the diagnosis as a gift. One mother within the Caucasian cohort mentioned, “. . . she’ll go why did I have to get diabetes and I’m like, I don’t know but it’s your gift so you’ve got to - there’s something you’re going to do with it, something very special that you’re going to do because you got it.” There were no obvious differences in the use of different techniques among the three ethnic groups.

Clinic ExperiencesTable 15: Clinic Qualities According to Parents

| Hisp | Good Clinic Qualities | Negative Clinic Qualities | Ways to Improve Clinic |
|----------|---------------------------------|---|---|
| 1 | Personnel | X | personnel/handouts – multilingual |
| 3 | Personnel | personnel - personality, phone system | System - phone svc |
| 6 | Personnel, Expertise | personnel – advice | Location |
| 11 | Personnel, location | personnel – insensitivity | more research, pump training |
| 16 | Personnel, Expertise | X | Nothing |
| 18 | Clinical results, personnel | X | Nothing |
| 22 | Clinical results | X | Nothing |
| | | | |
| Af Am | Good Clinic Qualities | Negative Clinic Experience | Ways to Improve Clinic |
| 2 | Personnel | system - phone coverage APRN vs. MD | System - APRN vs. MD |
| 4 | Technology available, personnel | X | More support groups |
| 7 | Personnel, clinical results | system - scheduling | Flexible scheduling |
| 8 | Personnel | X | Nothing |
| 12 | Dispense good info | X | X |
| 15 | Personnel | X | Info/assistance for financially disadvantaged |
| | | | |
| Cauc | Good Clinic Qualities | Negative Clinic Experience | Ways to Improve Clinic |
| 9 | Personnel, expertise | X | personnel - APRN vs. dietician/social worker |
| 10 | Personnel | system - visit structure | Flexible scheduling, more research updates |
| 13 | Personnel, technology available | Emotion associated c visit | Prettier bldg, more psych help, better dispense of info |
| 17 | Personnel | system - study | Flexible scheduling |
| 19 | Research knowledge | system - dispense of info, personnel - bedside manner, respect, roles | System - dispense of info; Personnel - role clarification |
| 20 | Research knowledge, personnel | X | System - phone svc |
| 21 | Personnel | X | Nothing |

Table 16: Clinic Qualities According to Children

| Hispanic | Good Clinic Qualities | Negative Clinic Qualities | Ways to Improve Clinic |
|------------------|---|----------------------------|--|
| 1 | Overall | x | Nothing |
| 3 | interaction with other kids, personnel, expertise | x | Nothing |
| 6 | Personnel | x | Nothing |
| 11 | Personnel | personnel - personality | Support groups, more education |
| 16 | Education | x | Nothing |
| 18 | Personnel | x | Nothing |
| 22 | Personnel | x | Nothing |
| | | | |
| African American | Good Clinic Qualities | Negative Clinic Qualities | Ways to Improve Clinic |
| 2 | \$ from studies; personnel | x | Nothing |
| 4 | Clinical results, personnel | x | Nothing |
| 7 | Clinical results, personnel | x | Nothing |
| 8 | Personnel | x | Support groups |
| 12 | Education | x | Clinic amenities, info for financially disadvantaged |
| 15 | Interaction with other kids | x | |
| Caucasian | Good Clinic Qualities | Negative Clinic Qualities | Ways to Improve Clinic |
| 9 | Personnel | x | Personnel |
| 10 | Personnel | personnel - bedside manner | X |
| 13 | Personnel | x | Nothing |
| 17 | Clinical results | Undisclosed | Nothing |
| 19 | Overall | Stress of unknown | Nothing |
| 20 | Education | X | Bigger rooms |
| 21 | Personnel, education | X | Nothing |

Views of the Yale Diabetes Clinic were overwhelmingly positive, with all three cohorts identifying positive aspects of the clinic (Tables 15 & 16). The quality of personnel was the quality most often cited as being a positive aspect of the clinic. Expertise of the clinic, clinical results obtained, and research knowledge were also mentioned across the various groups. A mother from the African American cohort spoke highly of the clinic, saying “. . . the people there are very friendly. They treat people with respect, doesn’t matter color, creed, religion, or whatever. I really love being at Yale.”

However there were negative experiences identified as well as some ways in which the clinic could improve. The negative experiences consisted of mainly personnel or system issues. Personnel issues included specific personalities of clinicians, whereas systems issues dealt with scheduling, phone coverage, visit structure, and method of information dissemination. Parental reports of negative clinic experiences were most often personnel in etiology within the Hispanic cohort, in contrast to the African American and Caucasian cohorts, who discussed mostly systems issues. A mother within the Caucasian cohort discussed an experience in which she felt information was not disseminated effectively to all clinicians, saying “(My child) was hospitalized for the first time . . . he had a gastrointestinal thing and there’s a thing you can do now, the clinic is advising as protocol where you give mini doses of glucagons and I had actually heard about this from another friend of mine and I asked the person at clinic who I called, who didn’t know what I was talking about, so then I talked to (another clinician) later, and she said, oh you were supposed to do this. Okay but I talked to someone at clinic who didn’t tell me to do it. . .”

When discussing ways to improve the clinic experience, personnel and systems issues were again discussed. They were similar across groups as seen in Table 15 with the exception of the Hispanic group, which in three cases could not identify any way in which the clinic could improve.

Table 17: Treatment Options

| Hispanic | Options Offered | Why taken (or not)? | Current Treatment Modality |
|------------------|-----------------|------------------------------|----------------------------|
| 1 | Pump | less freedom with pump | injection |
| 3 | Pump | discomfort/body image | injection |
| 6 | Pump | body image | injection |
| 11 | X | X | pump |
| 16 | Pump | X | injection |
| 18 | Pump | body image/sports comfort | injection |
| 22 | Pump | X | pump |
| | | | |
| African American | Options Offered | Why taken (or not)? | Current Treatment Modality |
| 2 | Pump | Sports | injection |
| 4 | Pump | HbA1c elevated | injection |
| 7 | Pen | HbA1c elevated | injection |
| 8 | Pump | HbA1c elevated | injection |
| 12 | Pump | comfortable c shots | injection |
| 15 | X | X | pump |
| | | | |
| Caucasian | Options Offered | Why taken (or not)? | Current Treatment Modality |
| 9 | Pump | X | pump |
| 10 | Pump | better control with pump | pump |
| 13 | Pump | X | pump |
| 17 | Pump | X | pump |
| 19 | Pump | X | pump |
| 20 | X | normalize schedule with pump | pump |
| 21 | Pump | normalize schedule with pump | pump |

An important part of clinic experience is the management decisions by clinicians, mode of insulin administration being a large part of those decisions. As shown in Table 17, all of the patients in the study had been offered the pump or were familiar with the pump, however the disparity in who was actually being treated with the pump was striking. All of the patients within the Caucasian cohort were treated with the pump, whereas there were only two on the pump with the African American and Hispanic cohorts respectively. Within the Hispanic cohort, reasons for not being on the pump were personal preference, including body image, discomfort with sports, and amount of freedom. One mother stated, “So she’s (my daughter) thinking maybe she’ll keep the injections, because with the injections she’s got more choice to eat different things and

she cooks the meal.” Within the African American cohort, three of the five subjects being treated with shots were doing so because their HbA1c was elevated, not because of personal preference.

Table 18: Health Care Experiences Outside of Yale Diabetes Clinic

| Hispanic | Negative Health Care Experiences | Child - Negative Health Care Experiences |
|------------------|---|--|
| 1 | X | X |
| 3 | Miscommunication with PMD | Personnel |
| 6 | X | X |
| 11 | Insurance coverage/disability | Disability |
| 16 | X | X |
| 18 | X | X |
| 22 | X | X |
| | | |
| African American | Negative Health Care Experiences | Child - Negative Health Care Experiences |
| 2 | X | X |
| 4 | X | X |
| 7 | Misdiagnosis at PMD; Unwillingness to refer to specialty center | Personnel |
| 8 | X | X |
| 12 | X | X |
| 15 | Misdiagnosis at PMD | X |
| | | |
| Caucasian | Negative Health Care Experiences | Child - Negative Health Care Experiences |
| 9 | Mistreatment of other kids | X |
| 10 | X | X |
| 13 | X | X |
| 17 | X | X |
| 19 | X | X |
| 20 | Inflexibility of treatment options | X |
| 21 | X | X |

There was no question in the interview guide specifically addressing negative health care experiences outside of the Yale Diabetes Clinic, however those were commonly brought up by the interviewees. As summarized in Table 17, there was no difference in the number of negative experiences in health care across ethnic groups, however there was a difference in the type of negative experience identified. Parents and children within the Hispanic cohort identified mostly negative experiences with miscommunication with their own and others' primary care clinicians, insurance providers, and disability coverage providers. Those within the African American cohort discussed issues with misdiagnosis within the health care system. The Caucasian cohort identified indirect experiences with poor treatment through other children and identified the inflexibility of treatment options with a previous health care provider. The African American and Hispanic cohorts seemed to identify quite a few more personal issues with misdiagnosis and mistreatment than the Caucasian cohort. When discussing her experience with clinicians after a misdiagnosis which led to her son being comatose before being diagnosed with diabetes, one African American mother said, “. . . till this day I don't trust the doctors, I question them to see, because even though they had right, they helped him get through, I am just letting you know how I feel and no one took that into consideration. And the doctor that was involved . . . I felt that he should apologize . . . I wasn't even thinking about suing him, I am trying to think about making things right.” One African American family also identified the issue of being the subject of racism within the setting of the health care system. Her child was asked to leave a diabetic support group on reasons which she did not agree with, and in discussing the

situation she stated, “I don’t know what it was, but I took it as being racist and I took it like that. And because the child that had the problem and she seemed to be, they always talking about ‘overlook her’ but they ain’t gone overlook mine. . .”

Discussion

Although multiple studies have shown that there is a disparity in the glycemic control of ethnic minorities, specifically the African American and Hispanic American populations, our recent investigations suggested that such disparities in our clinic were likely associated with low family income level. Various quantitative and questionnaire based studies have been completed to analyze these disparities, however few have conducted qualitative studies to discuss with families what their concerns and challenges are, an issue which is important in our clinic population. Although the mean HbA1c of the population studied was good (<8%) in each cohort, it is important to remember that treatment success includes quality of life and psychosocial health as well as glycemic control.(7) Therefore, an exploratory descriptive study with open-ended questions was conducted to identify and further analyze factors which influence the control of type 1 diabetes in patients of different ethnic groups but of similar low socioeconomic status. Within this section, the findings within each of the four categories addressed previously are compared to previous research, and limitations and future implications of the study are discussed.

View of Disease/Effect of Disease on Family

The view of disease and emotional response of disease given by most of the families were as expected overall, reflecting a description of anxiety, sadness, and feelings of isolation in both parents and children which closely matched those identified in previous studies. (8, 9) However as noted in the results, Hispanic families were more often unable to identify anything easy about coping with or managing diabetes, and

parents were more anxious after the diagnosis according to their children. These data seem to suggest that there is a difference in the way the Hispanic cohort coped with the disease. These issues may be related to language barriers with the health care community (although all of the subjects spoke English at the time of the interview and only 1 parent identified it as an issue), or possibly family structure (as several parents identified single parent status as making it more difficult for them). This may also be reflective of an increased responsibility of Hispanic parents for diabetes management in comparison to African American and Caucasian parents as identified in the Gallegos-Macias et al study and noted in this study. (4)

Many parents within the Hispanic cohort also identified their preoccupation with diabetes as comprising most or all of their time, a phenomenon which was not seen commonly in the study by Kovacs, et al examining parent's responses to the diagnosis of diabetes in their children. (9) The study demonstrated that only about 18% of mothers in the study were overinvolved with their children's care after the first year of diagnosis. It did mention, however, the possibility that extremes of involvement became more prevalent as years of diagnosis increase and metabolic control worsens. The study also used a sample which was 93% Caucasian, making it difficult to assess the effects of ethnicity and culture on parental involvement.

Interestingly, HbA1c did not vary as widely as expected between families who seemed to be "doing well" in terms of their emotional response and preoccupation with the diagnosis and those who seemed to be more emotionally devastated by the diagnosis and its management. This makes it difficult to conclude that a more emotionally stable and well adjusted family automatically translates into better controlled diabetes and vice

versa, however it does confirm the idea that successful diabetes treatment is reflected by more than just good glycemic control, and should always include addressing psychosocial issues which are complicated by such a diagnosis as well. (7)

Ability to Treat Disease

The increased number of children within the Hispanic cohort who identified the parent or equal responsibility in managing diabetes is reflective of results obtained in a study by Gallegos-Macias, et al comparing the difference in glycemic control between Hispanic and non-Hispanic white youth.(4) In that study, they noted that white non-Hispanic parents reported less supervision of their child's blood sugar testing as compared with Hispanic parents.

Financial, family, and cultural factors were all disproportionately expressed as important in the African American and Hispanic cohorts. Financial factors were discussed multiple times within both the African American and Hispanic cohorts despite no significant difference in mean income between these groups and the Caucasian cohort. Issues surrounding quality of job came up most often, possibly suggesting that although income was similar across the groups, the job security, benefits, and flexibility may have varied. In a sociology study on the incidence of job dismissal in African American and Caucasians in the early phase of their work (3 years of early work career), it was found that African Americans experienced dismissal at nearly twice the rate of whites despite similar credentials, background socioeconomic status, and labor market characteristics. It is possible that subconsciously the African Americans parents who brought up the concern about job security were aware of this disparity through personal experiences and

therefore hypervigilant and anxious about their job security. Although the study only compared African Americans and Caucasians, it is possible that Hispanic Americans experience the same phenomenon if the increased dismissal rate is in fact based on racial/ethnic discrimination. (10) In the study on parent's perceptions of factors which affect successful diabetes treatment, the idea "If the diabetes team treats all patients and families equally no matter what race or culture" was identified as important, and differed significantly by race. (11) The study population in that study was 81.5% white, 14.1% black, and 4.4% from other ethnic backgrounds.

Within family factors, the Hispanic cohort had many more single mothers than either of the other cohorts, and they identified single parenthood as making things more difficult for them. Families with two parent households often identified the spouse at some point in the interview as supportive and helpful in the management of the diabetes. These families were often the ones who seemed less negatively affected by the diagnosis and often appeared to be coping in a healthier way. It is difficult to identify whether this is secondary to more financial freedom, two parent household, or larger support system. As discussed in an article by Thompson, et al which compared the control of children in single mother vs. two parent families, children from single-mother families are at risk for poorer metabolic control and often experience more family stress and have access to fewer available resources.(12)

Ability to Cope with Disease

Families who seemed to be very at ease with the diagnosis were the ones who had an attitude of the child being their "special child" or their "hero". This was reviewed in

an article by Chernoff et al. which described the prevalence of positive thinking in mothers of children with chronic illnesses and how families had benefited from the diagnosis. (13) It was evident in this study that parents who were “positive thinkers” in reference to the diagnosis appeared much more comfortable with the diagnosis, and this was often reflected in the comfort of the child with the diagnosis as well.

As discussed in the previous section, cultural factors affecting diabetes management and coping were identified by the African American and Hispanic cohorts more often, discussing issues of cultural isolation. In a study analyzing patients’ perceptions of cultural factors affecting the quality of their medical encounters, the factors most discussed by both African Americans and Latino patients included health insurance-based, ethnicity-based, and social class-based discrimination. African Americans specifically discussed ethnic concordance of physician and patient, factors of knowledge and acceptance of alternative medicine and physician’s acceptance of spirituality in the role of the illness. In Latino patients, language-based discrimination was by far the most mentioned factor, followed by sensitivity to immigration and modesty, sensitivity to nutrition without stereotyping, and recognizing the importance of family. (14)

These groups also disproportionately brought up support groups as a tool to help them cope, raising the question of whether their increased desire for support groups was in response to the isolation felt more often in minority communities (in which the disease is much less prevalent than in majority communities). In the study on parent’s perception of factors that impact successful diabetes treatment, “If a child can join a support group

for children with diabetes” was ranked as important equally by African American and Caucasian parents, however this was not the case in the current study.(11)

One interesting difference between the cohorts was the mention of Yale Diabetes Clinic as a support system. It was mentioned four times within the Caucasian cohort; however it was only mentioned once in the other two cohorts by the African American family of high socioeconomic status. It is possible that this difference is reflective of a different experience of the physician-patient relationship by African American and Hispanic patients. In a study on the quality of patient-physician communication during medical visits in African American versus White patients, it was shown that the quality of visits with African American patients was poorer than those with White patients. The study involved the audio recording and analysis of primary care visits by reviewers who were not aware of the nature of the study. They found that there was more verbal dominance by physicians, less patient centeredness, and less positive affect exhibited in the interactions with African American patients.(15)

Support systems most often named throughout all three cohorts were family and friends. God or religion was also mentioned across the cohorts, consistent with the results in a paper on predictors of coping strategy, which said that patients of lower socioeconomic status used religious coping strategies more often. (16)

Yale Diabetes Clinic

Mode of insulin administration has been shown to impact metabolic control and decrease risk of hypoglycemic episodes. (17) Approximately 63% of the patients who attend the Yale Diabetes Clinic are treated with the insulin pump.(5) As stated previously, there

was a significant disparity in the mode of insulin administration between the cohorts. The important question raised is why the disparity exists. Although the HbA1c of each of the subjects in the African American cohort who were told their A1c was too high was indeed elevated (10.4, 8.4, and 7.8%), it is still striking that subjects with similar HbA1c's in the Caucasian and Hispanic cohorts were still treated with the pump. This disparity could be as a result of family issues which were not addressed in this study, but could also be a result of clinician bias. Also, the reasons given within the Hispanic cohort for not wanting the pump (i.e. less freedom with the pump, discomfort with sports) were often directly contradictory to the true benefits of the pump. This could be the result of miscommunication with health care providers or misunderstanding of the way in which the pump works. There are no studies in the literature currently discussing whether this disparity is apparent at other diabetes treatment centers, or what the etiology may be.

The disparity in number and type of negative health care experiences outside of the Yale Diabetes Clinic by African Americans and Hispanic patients could be explained in part by the previously mentioned study which showed poorer quality physician-patient communication during visits (15), and by language-based discrimination with physicians being such an important factor in the Latino community. (14) Both the Hispanic and African American cohorts identified issues with misdiagnosis and miscommunication, consistent with the results of the Johnson, et al study and the issue of language and language-based discrimination in the Napoles-Springer, et al study.

Limitations & Strengths

The major strength of this study is the fact that it allowed the participants to determine the hypothesis, therefore hopefully drawing honest conclusions on factors which affect the populations included. However, the sample size of this study was small, and the results warrant a future larger study to further investigate the issues encountered. Also, all patients involved are part of a specialized diabetes center in an urban area, therefore not necessarily reflective of patients who may be seen by primary care providers or in different environments.

Conclusions & Recommendations

In conclusion, there are identifiable differences in how people of different ethnic groups manage and cope with diabetes. Although these differences are likely multifactorial, with components of socioeconomic status, family structure, and family experiences involved, it is evident that ethnicity itself is an important factor. It is unclear through this study whether ethnicity is so important because of differences in culture of belief in the ethnic groups themselves or differences in the response of health care providers and society in general to people within the ethnic groups included in this study. Therefore it is important for health care providers to consider the various issues which can affect a patient's ability to manage and cope with their disease, however it is also important for them to monitor their own behavior and responses to the patient and to guard against subconscious responses solely on the basis of ethnicity or socioeconomic status. Further study is warranted to confirm the results identified and to expand on the themes noted.

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Appendix A

Interview Guide

For parents:

1. What is having a child with diabetes like for you?
2. What is it like to manage your child's diabetes?
3. What about it is difficult for you?
4. What about it is easy?
5. How has your child dealt with the diagnosis?
6. How do you and your child share the responsibility of managing the diabetes?
7. How would you describe your relationship with your child? Has it changed since the diagnosis?
8. How do you decide how much time to focus on diabetes in comparison to other things?
9. Who do you have to support you and your child?
10. What would make it easier for you and your child?
11. What treatment options for managing your child's diabetes have you discussed with the clinicians at the clinic?
12. Describe your experience at the Diabetes Clinic.
13. What could make your experience at the clinic better (or what makes it good)?
14. For purposes of the overall study, how do you classify yourself in terms of ethnicity?

For children:

1. What is having diabetes like for you?
2. How do you feel about the demands of controlling your diabetes?
3. What is the hardest part of having diabetes?

4. How do you and your parents share the responsibility of managing the diabetes?
5. How would you describe your relationship with your parents? Has it changed since the diagnosis?
6. How do you decide how much time to focus on diabetes in comparison to other things?
7. What do you think would make controlling diabetes easier for you?
8. Describe your experience at the Diabetes Clinic.
9. What would make your experience at the clinic better (or what makes it good)?

For both:

1. Describe a typical day for you (including diabetes care).
2. Who is the most responsible for managing the diabetes?

Appendix B

Coding Categories

1. Emotional Response of Parent to T1DM

Parent's description of her emotional reactions to her child's diagnosis and management. This includes emotion at diagnosis as well as emotions in response to later challenges and experiences, and parent's behavior changes through dealing with diagnosis. Also includes description of diagnosis and situations around diagnosis.

2. Parent's General View of T1DM

Parent's description of her general attitude about T1DM.

2a. This includes her perception of what is easy about dealing with T1DM.

2b. This includes her perception about what is hard about dealing with T1DM

3. Child's General View of T1DM

Child's description of her general attitude about T1DM.

3a. This includes her perception of what is easy about dealing with T1DM.

3b. This includes her perception about what is hard about dealing with T1DM

4. Parent's Perception of Emotional Response of Child

Parent's description of her observations of her child's emotional response to T1DM. This includes emotions and behaviors which the family noted at diagnosis as well as in response to management and everyday life with the disease.

5. Child's Perception of their Emotional Response to T1DM

This includes the child's emotional response to diagnosis as well as demands of management and everyday life with the disease.

5.5 Child's Perception of Emotional Response of Parent

Child's description of her observations of her parent's emotional response to T1DM.

6. Division of Responsibility

6a. Parent's description of division of responsibility in managing diabetes.

6b. Child's description of division of responsibility in managing diabetes.

7. Parent's Perception of Parent-Child Relationship

7a. Parent's description of her and her child's relationship as it exists outside of diabetes management

7b. Parent's description of how the relationship changed after diagnosis

8. Child's Perception of Parent-Child Relationship

8a. Child's description of her and her parent's relationship as it exists outside of diabetes management

8b. Child's description of how the relationship changed after diagnosis

9. Parent's Preoccupation with Disease

9a. Parent's perception of their own preoccupation with disease and how much time she spends thinking about or focusing on T1DM and issues related to diabetes

9b. Parental comment which infers parent's preoccupation (or lack of preoccupation) with disease, or which infer her worries

10. Child's Preoccupation with Disease

10a. Child's perception of how much time she spends thinking about or focusing on T1DM and issues related to diabetes.

10b. Child comment which infers child's preoccupation (or lack of preoccupation) with disease

11. Parental Perception of Accessible Support System

11a. Parental perception of who she has as a support system. This includes emotional, physical, and spiritual support.

11b. Parental perception of who her child has as a support system.

11.5 Child's Perception of Support System

Child's perception of who she has as a support system.

12. Parental Report of What Would Make Dealing with T1DM Easier

12a. Parental report of what they are lacking that would make treating diabetes easier for them

12b. Parental report of what they are lacking that would make coping with diabetes easier for them

13. Parental Report of What Has Made Dealing with T1DM Easier

13a. Parental report of what they already have or have had in the past that has made treating diabetes easier for them

13b. Parental report of what they already have or have had in the past which has made coping with diabetes easier for them

14. Child Report of What Would Make Dealing with T1DM Easier

14a. Child report of what they are lacking that would make treating diabetes easier for them

14b. Child report of what they are lacking that would make coping with diabetes easier for them

14.5 Child Report of What Has Made Dealing with T1DM Easier

14.5a. Child report of what they already have or have had in the past that has made treating diabetes easier for them

14.5b. Child report of what they already have or have had in the past which has made coping with diabetes easier for them

15. Parental Report of Treatment Options Offered

15a. Parental report of treatment options offered by the clinic.

15b. Parental report of why the treatment options were taken or not taken.

16. Parental Report of Negative Clinic Experience

Parental report of any negative experience with the clinic.

17. Child Report of Negative Clinic Experience

Child's report of any negative experience with the clinic.

18. Parental Report of Things Which Would Improve Clinic Experience

Parental report of how the Yale Diabetes Clinic could be improved.

19. Child Report of Things Which Would Improve Clinic Experience

Child's report of how the Yale Diabetes Clinic could be improved.

20. Parental Report of Clinic Qualities

Parental report of good or equivocal qualities about the clinic

21. Child Report of Clinic Qualities

Child report of good or equivocal qualities about the clinic

22. Parental Report of Behavioral Changes as a Result of T1DM

Parental report of specific changes in the behavior of the child, immediate family, or self which they view as a direct result of the diabetes diagnosis in the child

23. Parental Report of Previous Experience with Disease

Parental report of previous experiences with disease in the child and immediate family members. This includes how they believe those experiences determined their current behavior and feelings.

24. Parental Report of Typical Daily Schedule

This includes parental report of typical, average schedule including diabetes care.

24.5 Parental Report of Atypical Schedule

This includes parental report of atypical schedule when more intensive diabetes care or preparation is required

25. Child's Report of Typical Daily Schedule

This includes child's report of typical, average schedule including diabetes care.

25.5 Child's Report of Atypical Schedule

This includes child's report of atypical schedule when more intensive diabetes care or preparation is required

26. Parental Classification of Self and Family

Parental report of how she classifies herself and her family in terms of ethnicity. Includes report of child's identity (if different).

27. Parental Report of Financial Factors affecting T1DM Management

Includes any discussion of money, finances, ability to purchase supplies or necessities for good diabetes management. Also includes discussion of job issues.

28. Parental Report of Family Factors affecting T1DM Management

Includes discussion of family dynamics, parenting strategies, and support (or lack of support) from family

28.5 Child's Report of Family Factors affecting T1DM Management

Includes discussion of family dynamics and parenting strategies

30. Parental Report of School Factors affecting T1DM Management

Includes discussion of issues caused by/prevented by the school and parent's perception of the school's ability to monitor and manage her child's diabetes, and provide health education

30.5 Child's Report of School Factors affecting T1DM Management

Includes discussion of issues caused by/prevented by the school and child's perception of the school's ability to monitor and manage diabetes and provide health education

31. Parental Report of Cultural Factors affecting T1DM Management

Includes discussion of cultural issues affecting diabetes management, including language barriers, lifestyle issues, or issues of isolation due to culture, race, or ethnicity.

31.5 Child's Report of Cultural Factors affecting T1DM Management

Includes discussion of cultural issues affecting diabetes management, including language barriers, lifestyle issues, or issues of isolation due to culture, race, or ethnicity.

32. Parental Report of Negative Health Care Experiences

Includes discussion of negative experiences with the health care system (outside of experiences with the Yale Diabetes Center), and trust (or lack of trust) of clinicians, treatments, clinic systems

32.5 Child's Report of Negative Health Care Experiences

Includes discussion of negative experiences with the health care system (outside of experiences with the Yale Diabetes Center), and trust (or lack of trust) of clinicians, treatments, clinic systems

33. Method Used for Coping with Disease

Includes discussion (direct and indirect) of ways in which the parent assists child in coping, and methods which the family uses to cope

34. Parental Report of Societal Factors affecting T1DM management

Includes discussion about media and public perception of diabetes

35. Diabetes and Chemistry

Appendix C

Table 1: Demographics of Participants

| | African American (n=6) | Hispanic American (n=7) | Caucasian American (n=7) |
|--------------------------------------|---------------------------|----------------------------|-----------------------------|
| Female | 3 | 5 | 4 |
| Male | 3 | 2 | 3 |
| Age 10-12 | 2 | 2 | 2 |
| Age 13-15 | 2 | 3 | 2 |
| Age 16-18 | 2 | 2 | 3 |
| Avg income \pm SD | \$37,662 \pm \$9,935 | \$35,228 \pm \$10,479 | \$45,991 \pm \$11,632 |
| Mean HbA1c \pm SD | 7.6 \pm 1.8 | 7.3 \pm 1.3 | 7.4 \pm 1.0 |
| Number of pumps | 1 | 2 | 7 |
| Avg Duration of Diagnosis (years) | 6.3 \pm 3.1 | 4.0 \pm 3.7 | 6.1 \pm 3.5 |
| # Single Parent Households | 3 | 4 | 0 |
| # Two Parent Households | 4 | 3 | 7 |

Table 2: Demographics of Individual Participants

| Ethnicity | # | Age (Sex) | Median Income | HbA1c (Date) | Diabetes duration | Treatment method |
|------------------|----|-----------|------------------|----------------|----------------------|---------------------|
| African American | 2 | 12 M | 50,625 | 5.8 (3/15/05) | 2 years | Injection |
| African American | 4 | 12 F | 34,545 | 10.8 (2/23/05) | 10 years | Injection |
| African American | 5 | 13 M | 84,374 | 8.4 (3/23/05) | 8 years | Pump |
| African American | 7 | 17 M | 34,167 | 8.4 (4/5/05) | 7 years | Injection |
| African American | 8 | 13 F | 32,012 | 7.7 (3/22/05) | 8 years | Injection |
| African American | 12 | 16 M | 48,958 | 6.3 (5/16/05) | 6 years | Injection |
| African American | 15 | 15 F | 25,662 | 6.5 (6/27/05) | 6 years | Pump |
| Caucasian | 9 | 15 F | 41,295 | 5.7 (4/25/05) | 2 years | Pump |
| Caucasian | 10 | 16 M | 60,461 | 7.7 (5/4/05) | 7 years | Pump |
| Caucasian | 13 | 16 F | 49,500 | 8.3 (6/1/05) | 10 years | Pump |
| Caucasian | 17 | 17 F | 52,557 | 8.4 (7/27/05) | 10 years | Pump |
| Caucasian | 19 | 10 M | 52,212 | 7.0 (8/16/05) | 7 years | Pump |
| Caucasian | 20 | 15 M | 41,510 | 6.9 (8/15/05) | 6 years | Pump |
| Caucasian | 21 | 10 M | 24,401 | 8.0 (8/15/05) | 1 year | Pump |
| Hispanic | 1 | 14 F | 34,583 | 7.2 (3/8/05) | 12 years | Injection |
| Hispanic | 3 | 12 F | 19,044 | 9.4 (3/23/05) | 4 years | Injection |
| Hispanic | 6 | 15 M | 47,310 | 7.7 (4/5/05) | 1 year | Injection |
| Hispanic | 11 | 16 F | 41,250 | 7.3 (5/18/05) | 4 years | Pump |
| Hispanic | 16 | 11 M | 26,146 | 6.4 (7/27/05) | 1 year | Injection |
| Hispanic | 18 | 15 F | 32,012 | 5.3 (8/3/05) | 3 years | Injection |
| Hispanic | 22 | 14 M | 46,250 | 8.1 (7/27/05) | 3 years | Pump |

Table 3: Interview Information

| Interview Number | Parent Interviewed | Location of Interview |
|-------------------------|---------------------------|------------------------------|
| 1 | Mother | Home |
| 2 | Mother | Home |
| 3 | Stepfather | Home |
| 4 | Mother | Clinic |
| 5 | Mother | Home |
| 6 | Mother | Home |
| 7 | Mother | Home |
| 8 | Aunt (Guardian) | Home |
| 9 | Father | Home |
| 10 | Mother | Home |
| 11 | Mother | Home |
| 12 | Mother & Father | Home |
| 13 | Mother | Home |
| 14 | Mother | Home |
| 15 | Mother | Church |
| 16 | Mother | Home |
| 17 | Mother | Home |
| 18 | Mother | Home |
| 19 | Mother | Home |
| 20 | Mother | Home |
| 21 | Mother | Home |
| 22 | Father | Clinic |

Table 4: Emotional Response to Diabetes

| Hispanic | Emotional Response of Parent to T1DM | Parent's Perception of Child's Emotional Response | Emotional Response of Child to T1DM |
|------------------|--|--|--|
| 1 | Awful, depression | "Wanted to die", isolation, discomfort | Frustration |
| 3 | Traumatized, challenged, fear, anxiety, guilt, resentment, frustration | Resentment, hate, needy | "Want it to go away", anger, isolation |
| 6 | Anxiety | Depression, anger | x |
| 11 | Fear, anger, fatigue, stress, anxiety, embarrassment | Brave | x |
| 16 | Anxiety | Anxiety, isolation, why me? | Fear, isolation |
| 18 | Fear, anxiety | Fear, why me?, acceptance | Bothersome |
| 22 | Difficulty | Depression, acceptance | Annoying |
| | | | |
| African American | Emotional Response of Parent to T1DM | Parent's Perception of Child's Emotional Response | Emotional Response of Child to T1DM |
| 2 | Anxiety, "wreck", adjustment | Why me?, acceptance | No adjustment |
| 4 | Why? Fear | Isolation, why me? | Isolation |
| 7 | Stress | Anger, suicidal, felt like a burden/disliked, mortality inevitable | Embarrassment, acceptance |
| 8 | Anxiety | Good, minimal response | Anger, fun |
| 12 | X | Frustration, acceptance | Aggravation |
| 15 | Not end of world | No response | Fun |
| | | | |
| Caucasian | Emotional Response of Parent to T1DM | Parent's Perception of Child's Emotional Response | Emotional Response of Child to T1DM |
| 9 | Fear, adaptation, guilt | Anxiety, courage | Painful, why me? |
| 10 | Anxiety, hypervigilance | Afraid of death, challenged, acceptance | x |
| 13 | Anxiety, fatigue, hypervigilance, isolation | Minimal response | Fine |
| 17 | Hypervigilance, anxiety | Minimal response | x |
| 19 | Hatred, sadness, frustration, disappointment, stress, depression | Why me?, depression, conscientious | Stressful, overwhelming, why me? |
| 20 | Fear | No tears, calm | x |
| 21 | Anxiety | Anger, pride | Fun |

Table 5: Parent's General View of Diabetes

| Hisp | Parent's General View of T1DM | Parent's View of Easy | Parent's View of Hard |
|-------|--|-----------------------|--|
| 1 | Importance of child's responsibility, self sufficiency; Hard work 150% | Self sufficient child | Teenage rebellion |
| 3 | X | Nothing | Emotional response of child |
| 6 | X | Nothing | Anxiety of the unknown |
| 11 | Inc responsibility, selflessness | Pump | Anxiety about night, finding a balance |
| 16 | Hard | Nothing | Child adherence |
| 18 | Not that hard; scary in past | Self sufficient child | Managing routine |
| 22 | Inc responsibility | Pump | Child adherence |
| | | | |
| Af Am | Parent's General View of T1DM | Easy | Hard |
| 2 | Normal; saved the family | Self-sufficient child | Anxiety |
| 4 | X | Nothing | Anxiety of unknown |
| 7 | Inc work; changed parent for better; need for parent-child partnership | Relationship | Hypervigilance |
| 8 | Not bad | Self-sufficient child | Child adherence |
| 12 | Big change, not difficult, routine | Familiarity c routine | Managing numbers in atypical situations |
| 15 | Inc focus on child | Pump | Child adherence |
| | | | |
| Cauc | Parent's General View of T1DM | Easy | Hard |
| 9 | Part of life, no extra stress | Self-sufficient child | Remembering to be hypervigilant |
| 10 | Not that bad | Ordering supplies | Emotional response to nonadherence of child |
| 13 | Isolating, brings family together, increased organization | X | Being away from child |
| 17 | Challenging | If child is adherent | Teenage rebellion |
| 19 | Stressful | Food choices | Anxiety of unknown, emotional response of both of DM regimen |
| 20 | Not so bad | Pump, food choices | Emotional response of child |
| 21 | Routine | Daily routine | Emotional response of child |

Table 6: Child's General View of Diabetes

| Hisp | Child's General View of T1DM | Child's View of Easy | Child's View of Hard |
|-------|--|---------------------------------------|--|
| 1 | X | X | Managing blood sugar |
| 3 | X | Self sufficiency | Restrictions in school; routine |
| 6 | Inc responsibility; not disease, just condition | Nothing | Managing blood sugar |
| 11 | Normal; Self responsibility & partnership with parents important; No reason to feel ashamed | Nothing | Routine; Inc responsibility |
| 16 | Hard, challenging | Knowing routine & limitations | Administering shots |
| 18 | Weird, different | Eating, everything | Routine |
| 22 | Hard | Pump | Adherence to diet |
| | | | |
| Af Am | Child's General View of T1DM | Easy | Hard |
| 2 | Regular; makes me special | Everything | Writing blood sugar |
| 4 | Boring, unfair | X | Managing blood sugar |
| 7 | Fun sometimes; allows me to meet new people; not limiting (i.e. in sports); must learn to be self sufficient | Excuse to eat well | Checking blood sugar, giving shots, sports |
| 8 | Fun sometimes; makes me mad sometimes | X | Adherence to diet |
| 12 | Extra work | Checking blood sugar | Adherence to diet |
| 15 | Fun, frustrating | Checking blood sugar & bolusing; pump | Adherence to diet |
| | | | |
| Cauc | Child's General View of T1DM | Easy | Hard |
| 9 | Hard & easy; a pain | Everything | Managing blood sugar |
| 10 | Care about future, so put higher demands for control on myself | Technology | Atypical schedule |
| 13 | Normal | Pump | Managing blood sugar |
| 17 | "Just a disease I've got to live with" | Administering insulin | Managing blood sugar |
| 19 | X | Routine | Wondering why me? |
| 20 | Annoying | Counting carbs | Checking blood sugar |
| 21 | Painful, fun, annoying | Changing cartridge | Inserting site |

Table 7: Relationships

| Hisp | Parent-Child Relationship | How it Changed | Child-Parent Relationship | How it Changed |
|-------|-----------------------------|--|----------------------------|----------------------------|
| 1 | Good | More love | Good | Early dx |
| 3 | Good | Regression of child | Good c Dad, Bad c Mom | More attention from parent |
| 6 | Good | Teenage rebellion; inc difficulty | Good | No change |
| 11 | x | Closer | Normal, OK | No change |
| 16 | Good, could improve | No change | Good | More strict |
| 18 | Good | Closer | Close | More anxiety from parent |
| 22 | Great | Closer | Good | More concern from parent |
| | | | | |
| Af Am | Parent-Child Relationship | How it Changed | Child-Parent Relationship | How it Changed |
| 2 | Very nice | Closer | Good | No change |
| 4 | Good, close | No change | Okay | No change |
| 7 | Ups & downs, overprotective | Closer | Good | Closer |
| 8 | Good | x | Good | Closer b/c custody change |
| 12 | Good | No change | Good | No change |
| 15 | Great | No change | Good | Closer |
| | | | | |
| Cauc | Parent-Child Relationship | How it Changed | Child-Parent Relationship | How it Changed |
| 9 | Close | No change | Wonderful | No change |
| 10 | Good | Stronger | X | x |
| 13 | Good | Early dx | Good | Early dx |
| 17 | Rocky 2 to anger issues | Early dx | Bad before, getting better | No change |
| 19 | Very close | Parent c more authoritarian role | Good | Early dx |
| 20 | Good | Parent's c bigger role in child's life | Okay | Early dx |
| 21 | Close | No change | Close | Closer |

Table 8: Preoccupation with Disease

| Hispanic | Parent's Preoccupation | Inferred Preoccupation with Disease | Child's Preoccupation | Child's Perception of Parent's Emotional Response |
|------------------|------------------------|---|-----------------------|---|
| 1 | 80-90% time | X | with routine | X |
| 3 | Minimal | Always | with routine | Stressful, hatred, doesn't care |
| 6 | Always | Always | none | X |
| 11 | Always | Always | with routine | X |
| 16 | Always | X | always | X |
| 18 | With routine | X | with routine | More worry |
| 22 | Always | X | with routine | More concern |
| | | | | |
| African American | Parent's Preoccupation | Inferred Preoccupation with Disease | Child's Preoccupation | Child's Perception of Parent's Emotional Response |
| 2 | None | With sports | with routine | X |
| 4 | Minimal | X | depends on BS | X |
| 7 | A lot | X | always | X |
| 8 | A lot | X | with routine | X |
| 12 | Always | X | minimal | X |
| 15 | With routine | X | with routine | Fear of death |
| | | | | |
| Caucasian | Parent's Preoccupation | Inferred Preoccupation with Disease | Child's Preoccupation | Child's Perception of Parent's Emotional Response |
| 9 | None | x | with routine | X |
| 10 | With routine | Randomly worry about future | depends on BS | X |
| 13 | Depends on blood sugar | Randomly worry about future & social impact | with routine | X |
| 17 | Depends on blood sugar | x | minimal | X |
| 19 | Always | Middle of night uncertainty | with routine | X |
| 20 | With routine | x | minimal | X |
| 21 | With routine | Randomly worry about future | a lot | X |

Table 9: Division of Responsibility

| Hispanic | Parent's Responsibility | Child's Responsibility |
|--------------|-------------------------|------------------------|
| 1 | Equal | Equal |
| 3 | Parent | Parent |
| 6 | Child | Child |
| 11 | Child | Child |
| 16 | Equal | Equal |
| 18 | Child | Child |
| 22 | Child | Parent |
| | | |
| Af Am | | |
| 2 | Child | Child |
| 4 | Child | Child |
| 7 | Varies | Child |
| 8 | Child | Child |
| 12 | Equal | Child |
| 15 | Equal | Child |
| | | |
| Cauc | | |
| 9 | Child | Child |
| 10 | Child | Child |
| 13 | Child | Child |
| 17 | Parent | Parent |
| 19 | Equal | Equal |
| 20 | Child | Child |
| 21 | Child | Child |

Table 10: Ease of Treatment

| Hispanic | What Has Made Treatment Easier for Parent | What Would Make Treatment Easier for Parent | What Has Made Treatment Easier for Child | What Would Make Treatment Easier for Child |
|--------------|---|---|--|--|
| 1 | Accessibility of PMD | new technology | X | inc guidance |
| 3 | X | X | Staying c routine | x |
| 6 | X | stem cells/cure | X | new technology |
| 11 | Pump | financial stability, more pump training & education | X | exercising, increased public awareness |
| 16 | X | pump, adherence of child | X | cure |
| 18 | books, carb counting | cure, in house nutritionist | X | pump |
| 22 | X | new technology | pump | new technology |
| | | | | |
| Af Am | | | | |
| 2 | X | Pump | X | nothing |
| 4 | Accessibility of Yale | X | Praying | Not sure, praying |
| 7 | X | X | X | Good DM care |
| 8 | Pump | cure, new technology | Pump | Not sure |
| 12 | X | new pump, better insurance | X | Nothing |
| 15 | Pump | | X | New technology |
| | | | | |
| Cauc | | Cure | | |
| 9 | Pump | new technology | pump | cure |
| 10 | Pump | cure, new technology | new technology, pump | New technology |
| 13 | pump, better glucometer | Nothing | pump | Not sure, cure |
| 17 | X | new technology; clinic improvement | insulin | Cure |
| 19 | X | cure, new technology | X | New technology |
| 20 | Pump | Nothing | X | New technology |
| 21 | X | | X | Cure, new technology |

Table 11: Parental Identification of Factors

| Hispanic | Financial Factors | Family Factors | School Factors | Cultural Factors |
|------------------|---|----------------------------------|-------------------------|---|
| 1 | X | Single mom | X | Language |
| 3 | X | Uninvolved mother | X | X |
| 6 | Needs better job; house (3 fam members share same BR) | Single mom, uninvolved father | X | Immigration - isolation from family in US, different food preferences |
| 11 | Healthy food is expensive, needs better job, good insurance | X | X | Immigration - isolation from family |
| 16 | Job - working at night | Single mom | X | X |
| 18 | Multiple jobs to be financially stable | Single mom | X | X |
| 22 | Both parents work | X | X | X |
| | | | | |
| African American | Financial Factors | Family Factors | School Factors | Cultural Factors |
| 2 | X | X | Neg - lack of education | Old fashioned mindset/lack of education and understanding in AfAm community |
| 4 | X | Young mom | X | X |
| 7 | Unstable job security, transportation | Family fear of treating diabetes | Neg before, pos now | Question of racism |
| 8 | X | X | Pos | X |
| 12 | X | X | X | X |
| 15 | Expense of meds, poor insurance | X | X | X |
| | | | | |
| Caucasian | Financial Factors | Family Factors | School Factors | Cultural Factors |
| 9 | X | X | X | X |
| 10 | X | X | Pos | X |
| 13 | X | X | X | X |
| 17 | X | X | X | X |
| 19 | X | X | Neg | X |
| 20 | X | Unhelpful family support | X | X |
| 21 | X | X | X | X |

Table 12: Child Identification of Factors

| Hisp | Child - Family Factors | Child - School Factors | Child - Cultural Factors |
|-------|---------------------------------------|-------------------------|----------------------------|
| 1 | X | X | x |
| 3 | Uninvolved mother, rocky relationship | Neg | Food preferences, language |
| 6 | X | X | x |
| 11 | X | Neg | x |
| 16 | X | X | x |
| 18 | X | X | x |
| 22 | X | X | x |
| | | | |
| Af Am | Child - Family Factors | Child - School Factors | Child - Cultural Factors |
| 2 | X | Neg - lack of education | |
| 4 | X | X | x |
| 7 | X | Neg | x |
| 8 | X | X | x |
| 12 | X | X | x |
| 15 | X | X | x |
| | | | |
| Cauc | Child - Family Factors | Child - School Factors | Child - Cultural Factors |
| 9 | X | X | x |
| 10 | X | X | x |
| 13 | X | X | x |
| 17 | X | X | x |
| 19 | X | X | x |
| 20 | X | X | x |
| 21 | X | X | x |

Table 13: Support Systems Identified

| Hisp | Parent's Support System | Parent's Perception of Child's Support System | Child's Support System |
|-------|---|---|------------------------|
| 1 | Husband in past, now nobody | X | X |
| 3 | Friend, ex-coworker | father's friend, nurse, school social worker, principal | X |
| 6 | None | X | X |
| 11 | Friends, co-workers, husband, kids | X | Friends |
| 16 | None | X | X |
| 18 | Child, Friend | X | X |
| 22 | God | X | x |
| | | | |
| Af Am | Parent's Support System | Parent's Perception of Child's Support System | Child's Support System |
| 2 | Husband, friends, family | Grandfather, friend with DM, stepfather, book | friend with T2DM |
| 4 | Child's father, family | Friends with DM | friend with DM |
| 7 | Family | Teachers, classmates, diabetic support group, sister | Friends |
| 8 | None, husband, child's father, family, friend | X | X |
| 12 | None, religion | X | X |
| 15 | God, family | God | X |
| | | | |
| Cauc | Parent's Support System | Parent's Perception of Child's Support System | Child's Support System |
| 9 | Church, friends | X | X |
| 10 | Yale, nobody in community but okay with that, school | Friends | X |
| 13 | Nobody for psych support, friend, husband, daughter, Yale | X | X |
| 17 | Family, Yale | X | X |
| 19 | Friend, Yale, sister, child's teacher/school, books, websites | X | X |
| 20 | Husband, family | Aunt, friends | X |
| 21 | Yale | Friends in past, none now after move | Mom |

Table 14: Coping Mechanisms

| Hisp | Would Make Coping Easier for Parents | Has Made Coping Easier for Parents | Would Make Coping Easier for Child | Has Made Coping Easier for Child | Method for Coping |
|-------|--|---|---|---------------------------------------|--|
| 1 | Support group | Accessibility of PMD, pump | kid support groups | x | Humor |
| 3 | resolution of family issues | X | better family dynamics | clinic, D/C of pump | X |
| 6 | financial stability, better housing | X | X | x | Normalization |
| 11 | X | Pump | kid support groups | x | Humor |
| 16 | Support group | X | X | x | X |
| 18 | X | X | X | x | Normalization |
| 22 | X | X | X | x | Faith in God |
| | | | | | |
| Af Am | What Would Make Coping Easier for Parents | What Has Made Coping Easier for Parents | What Would Make Coping Easier for Child | What Has Made Coping Easier for Child | Method for Coping |
| 2 | Cure | X | X | x | Normalization, humor, child "saved" family |
| 4 | Support group | Accessibility of Yale | X | x | Bright side; normalization; keeping child active |
| 7 | adult daycare for sick days | school program | X | x | X |
| 8 | X | X | kid support groups | x | Normalization, bright side, religion |
| 12 | X | X | X | x | Spirituality, religion |
| 15 | X | X | | | |
| | | | What Would Make Coping Easier for Child | What Has Made Coping Easier for Child | Method for Coping |
| Cauc | What Would Make Coping c T1DM Easier for Parents | What Has Made Coping Easier for Parents | X | x | Normalization |
| 9 | X | X | X | x | Active lifestyle |
| 10 | X | family is closer | X | x | Bright side |
| 13 | control of child's habits, increased family support and friend with DM for child | X | X | x | X |
| 17 | X | X | X | x | X |

| | | | | | |
|----|--|--|---|---|-----------------------|
| 19 | X | other studies, psychologist with one study | X | x | X |
| 20 | better mode of communication for child | X | X | x | DM is child's gift |
| 21 | X | Yale | | | |

Table 15: Clinic Qualities According to Parents

| Hisp | Good Clinic Qualities | Negative Clinic Qualities | Ways to Improve Clinic |
|----------|------------------------------------|---|---|
| 1 | Personnel | X | personnel/handouts – multilingual |
| 3 | Personnel | personnel - personality, phone system | System - phone svc |
| 6 | Personnel, Expertise | personnel – advice | Location |
| 11 | Personnel, location | personnel – insensitivity | more research, pump training |
| 16 | Personnel, Expertise | X | Nothing |
| 18 | Clinical results, personnel | X | Nothing |
| 22 | Clinical results | X | Nothing |
| | | | |
| Af Am | Good Clinic Qualities | Negative Clinic Experience | Ways to Improve Clinic |
| 2 | Personnel | system - phone coverage APRN vs. MD | System - APRN vs. MD |
| 4 | Technology available, personnel | X | More support groups |
| 7 | Personnel, clinical results | system – scheduling | Flexible scheduling |
| 8 | Personnel | X | Nothing |
| 12 | Dispense good info | X | X |
| 15 | Personnel | X | Info/assistance for financially disadvantaged |
| | | | |
| Cauc | Good Clinic Qualities | Negative Clinic Experience | Ways to Improve Clinic |
| 9 | Personnel, expertise | X | personnel - APRN vs. dietician/social worker |
| 10 | Personnel | system - visit structure | Flexible scheduling, more research updates |
| 13 | Personnel, technology available | Emotion associated c visit | Prettier bldg, more psych help, better dispense of info |
| 17 | Personnel | system – study | Flexible scheduling |
| 19 | Research knowledge | system - dispense of info, personnel - bedside manner, respect, roles | System - dispense of info; Personnel - role clarification |
| 20 | Research knowledge, personnel | X | System - phone svc |
| 21 | Personnel | X | Nothing |

Table 16: Clinic Qualities According to Children

| Hisp | Good Clinic Qualities | Negative Clinic Qualities | Ways to Improve Clinic |
|-------|---|----------------------------|--|
| 1 | Overall | X | Nothing |
| 3 | interaction with other kids, personnel, expertise | X | Nothing |
| 6 | Personnel | X | Nothing |
| 11 | Personnel | personnel - personality | Support groups, more education |
| 16 | Education | X | Nothing |
| 18 | Personnel | X | Nothing |
| 22 | Personnel | X | Nothing |
| | | | |
| Af Am | Good Clinic Qualities | Negative Clinic Qualities | Ways to Improve Clinic |
| 2 | \$ from studies; personnel | X | Nothing |
| 4 | Clinical results, personnel | X | Nothing |
| 7 | Clinical results, personnel | X | Nothing |
| 8 | Personnel | X | Support groups |
| 12 | Education | X | Clinic amenities, info for financially disadvantaged |
| 15 | Interaction c other kids | X | |
| Cauc | Good Clinic Qualities | Negative Clinic Qualities | Ways to Improve Clinic |
| 9 | Personnel | X | Personnel |
| 10 | Personnel | personnel - bedside manner | X |
| 13 | Personnel | X | Nothing |
| 17 | Clinical results | Undisclosed | Nothing |
| 19 | Overall | Stress of unknown | Nothing |
| 20 | Education | X | Bigger rooms |
| 21 | Personnel, education | X | Nothing |

Table 17: Treatment Options

| Hispanic | Options Offered | Why taken (or not)? | Current Treatment Modality |
|------------------|-----------------|------------------------------|----------------------------|
| 1 | Pump | less freedom with pump | injection |
| 3 | Pump | discomfort/body image | injection |
| 6 | Pump | body image | injection |
| 11 | X | X | pump |
| 16 | Pump | X | injection |
| 18 | Pump | body image/sports comfort | injection |
| 22 | Pump | X | pump |
| | | | |
| African American | Options Offered | Why taken (or not)? | Current Treatment Modality |
| 2 | Pump | Sports | injection |
| 4 | Pump | HbA1c elevated | injection |
| 7 | Pen | HbA1c elevated | injection |
| 8 | Pump | HbA1c elevated | injection |
| 12 | Pump | comfortable c shots | injection |
| 15 | X | X | pump |
| | | | |
| Caucasian | Options Offered | Why taken (or not)? | Current Treatment Modality |
| 9 | Pump | X | pump |
| 10 | Pump | better control with pump | pump |
| 13 | Pump | X | pump |
| 17 | Pump | X | pump |
| 19 | Pump | X | pump |
| 20 | X | normalize schedule with pump | pump |
| 21 | Pump | normalize schedule with pump | pump |

Table 18: Health Care Experiences Outside of Yale Diabetes Clinic

| Hisp | Negative Health Care Experiences | Child - Negative Health Care Experiences |
|-------|---|--|
| 1 | X | X |
| 3 | Miscommunication with PMD | Personnel |
| 6 | X | X |
| 11 | Insurance coverage/disability | Disability |
| 16 | X | X |
| 18 | X | X |
| 22 | X | X |
| | | |
| Af Am | Negative Health Care Experiences | Child - Negative Health Care Experiences |
| 2 | X | X |
| 4 | X | X |
| 7 | Misdiagnosis at PMD; Unwillingness to refer to specialty center | Personnel |
| 8 | X | X |
| 12 | X | X |
| 15 | Misdiagnosis at PMD | X |
| | | |
| Cauc | Negative Health Care Experiences | Child - Negative Health Care Experiences |
| 9 | Mistreatment of other kids | X |
| 10 | X | X |
| 13 | X | X |
| 17 | X | X |
| 19 | X | X |
| 20 | Inflexibility of treatment options | X |
| 21 | X | X |

