Diabetes In Somali Children In Minneapolis and St.Paul, Minnesota

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Dedication

I dedicate this work to my husband, Osama, to my precious boys, Ammar and Malik for drawing a smile on my face despite deleting different electronic drafts of this thesis while mommy was trying to multi task, and to my parents who have supported me through many difficult times and to whom I shall forever be indebted.

Abstract

Minnesota is home to the largest population of Somalis in the United States (US). The 2011 United States Census Bureau estimates that there are more than 32,000 individuals of Somali origin [1, 2], and many believe there is a significant underestimation of this number. Somalis originate from a distinct geographic region in East Africa, and have obvious similarities in physical features suggesting relative genetic homogeneity. In contrast, most African Americans descend from various areas in Africa, and have experienced significant intermingling amongst themselves and with other populations rendering this population less homogeneous. Thus, not surprisingly, diabetes may differ between Somalis and other African Americans. Type 1 diabetes (T1D) is an autoimmune disease of heterogeneous etiology [3-5]. Carrying specific human leukocyte antigen (HLA) alleles determines an individual's genetic risk for developing T1D. It has been established that these alleles may differ between populations [3, 6]. This dissertation describes some of the clinical characteristics, diabetes autoantibody and HLA allele profiles, and explores cultural beliefs related to diabetes in Somali children with T1D who live in the Twin Cities, Minnesota. These studies have led to two papers, which have been submitted for peer-reviewed publication.

My primary project, describes the immune and genetic basis of T1D in a group of Somali children in the Twin Cities, Minnesota by determining human leukocyte antigen (HLA) alleles and diabetes autoantibodies. Twenty-seven Somali children ≤19 years treated for T1D at the University of Minnesota and Children's Hospitals and Clinics of Minnesota from January 1st, 2012 to January 31st, 2014, participated. Venous blood samples for HLA alleles, and diabetes autoantibodies (GAD65, islet antibodies, insulin antibodies and ZnT8) were obtained. In these 27 children, the most common HLA phenotype was DR3. Strikingly, 92% of subjects carried this phenotype (allele frequency 63%). Another common genotype was DR13 (27%, allele frequency 14%). There was a relatively low frequency of DR4 (15%, allele frequency 8%). This genetic pattern is very different from that of Caucasians or African Americans. All 27 participants had positive elevation of at least one diabetes autoantibody confirming that this is autoimmune diabetes. GAD65 antibodies were found in 56% of subjects, IA-2 in 33%, and ZnT8 in 22%.

My second project was a cross-sectional study that describes cultural beliefs related to diabetes in Minnesota Somali children with T1D, and compares their diabetes control to that of non-Somali children with T1D. Demographic and clinical data were collected by history and from medical records of Somali children ≤19 years with T1D followed at the University of Minnesota Children's Hospital and Children's Hospitals and Clinics of Minnesota. A survey was administered to parents of all participants and to children aged ≥12 years. Twenty-five Somali children participated, with 24 parent-child pairs (2 siblings). In general, diabetes was well accepted. Seventy-one percent of parents indicated the child was "the same as before" other than having to do diabetes cares. Families were coping well, and the child was not treated differently than siblings. Performance of routine medical cares was described as the hardest part about having diabetes, but this was not related to conflicts with traditional culture or religion. One notable exception was difficulty performing carbohydrate counting on Somali foods. Our education materials were not helpful when it came to the traditional Somali diet. Respondents were appreciative of the education provided by the diabetes team. Less than 10% used herbal supplements in addition to insulin. Mean HbA1c in Somali children was higher than the overall pediatric clinic average, 9.5±1.6% vs 8.8±1.6 (p =0.01). The difference was largely due to adolescent patients.

These two studies suggest that autoantibody and HLA profiles of Somali children with diabetes are consistent with autoimmune T1D, and that their HLA profile is unique compared to African Americans with T1D. The data also highlight that the majority of Somali families cope well with diabetes, and that glycemic control in adolescents is worse than that of non-Somali peers.

Findings from this study beg the question of whether differences in diabetes between Somali children and their non-Somali peers is merely a result of these differences in HLA alleles, or whether other factors influence glycemic control in this population. Data from this study will be used to target diabetes education and to provide culture-specific educational resources to improve the experience of living with this chronic condition.

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Chapter One: Introduction

A large number of Somalis fled the civil war in Somalia, in the last two decades, seeking refuge in several parts of the globe such as East Africa, Europe, the United States (US), and Canada, and changing the demographic profiles of the hosting countries [7]. The US state of Minnesota (MN), while not an intuitive destination choice for people accustomed to a desert climate, is known for a low unemployment rate, a strong social welfare system, and religious tolerance. A small group of Somali refugees was initially assigned to live in Minnesota by the US State Department working with local relief agencies; friends and relatives soon followed when word about the favorable job market in Minnesota had spread [8]. Minnesota now has the largest number of Somali immigrants in the US, estimated at 32,000 individuals, a figure thought to be an under estimation [1] [9]. I had first developed interest in studying diabetes in the Somali population during my pediatric endocrinology fellowship training at the University of Minnesota, when I noticed in my clinical practice that relatively large numbers of Somali children have type 1 diabetes (T1D), an observation shared by pediatric endocrinologists in the three main practice groups that treat pediatric diabetes in the Twin Cities, MN. This sparked my interest in looking for genetic risk factors in Somalis. Surprisingly, little has been published about diabetes in this population. Therefore, one of the aims of the work described in this dissertation was to better describe the genetic and autoimmune characteristics of diabetes in Somali children, and to shed light on the culturally-specific aspects related to having diabetes in this community.

T1D affects approximately 1 in 400-600 children in the US, and the incidence is increasing [10, 11]. Its etiology is multifactorial, with genetic, immunologic and environmental components. Several genes have been described

in association with T1D, however, human leukocyte antigen (HLA) class II genes, located on chromosome 6, are by far the main genetic determinants of an individual's risk for developing T1D [12, 13]. Each individual carries a pair of alleles (i.e. copies of a gene). The risk of T1D is related to specific human leukocyte antigen (HLA) alleles which may differ between populations [4, 8]. Certain HLA alleles confer greater risk, such as DR3 (HLA-DRB1*03) or DR4 (HLA-DRB1*04) alleles with DQ8 (DQB1*03:02), while others are protective (DQB1*0602) [4, 14].

Detecting unique HLA allele profiles in Somali children with T1D could help explain whether their relatively high rate of T1D is due to –at least in part- to carrying high-risk HLA alleles. These data could potentially be used in risk assessment for T1D.

Unfortunately, few data from Somalia describing the HLA types of children with T1D exist. In a small Finnish study by Oilinki et al, HLA analysis of 12 young Somali children with diabetes showed a high frequency of DR3, high frequencies of DR13 and DR1, and no DR4 [15]. This deferred from the typical T1D profile in Finland, with DR4 predominance. Interestingly, the prevalence of T1D in Somali children was equal to that of all Finnish children, generally considered the highest in the world [15].

HLA type confers genetic risk. Once autoimmune destruction of beta cells begins, autoantibodies can be detected in the blood (long before blood glucose abnormalities appear). Autoantibodies are not considered to be agents of beta cell destruction, but simply immunologic markers. These include: glutamic acid decarboxylase (GAD65) antibodies, insulin autoantibodies (IAA), islet cell antibodies (ICA), insulinoma antigen 2 antibodies (IA-2, also known as ICA512), and zinc transporter 8 (ZnT8) antibodies [4]. The presence of positive autoantibodies supports a diagnosis of T1D. Similar to the Finnish study by Oilinki et al, where 67% of 12 Somali children were positive, O'Connor et al reported in their study involving 60 East African immigrants (Kenya, Uganda,

Ethiopia, Eritrea, and Somalia), that nearly 66% of immigrant children tested positive for at least one diabetes autoantibody type within 1 month of diagnosis of T1D [16]. GAD65 was the most common at 62.5%, followed by IAA (34.6%), IA-2 (25%) and ICA (14.3%)[16]. The Finnish study by Oilinki et al reported that 57% had ICA, 50% had GAD65, 33% had IA-2, and 33% had ZnT8 antibodies [15].

This dissertation describes HLA types and diabetes autoantibodies in a larger group of Somali children with T1D than has ever been published in the medical literature.

Proper diabetes control is crucial to minimize risk for potential future complications [17]. Children from ethnic minorities are known to have worse diabetes control than non-minority children [15, 18, 19]. Studies of adult Somali patients with type 2 diabetes (T2D) have shown worse glycemic control compared to non-Somalis [20]. Similarly, glycemic control in 15 Somali children in a Finnish study was higher than non-Somali children, with a mean HbA1c of 9.3±2.2% compared to 8.3±1.5%, respectively ($p<0.001$) [15]. Data from the Diabetes Control and Complications Trial (DCCT) indicate that 5-7 years of poor glycemic control, even during adolescence and young adulthood, results in an increased risk for microvascular and macrovascular complications in the subsequent 6-10 year period [21]. Thus, in this dissertation, glycemic control in Somali children with T1D is compared to that of their non-Somali peers with T1D followed in the pediatric diabetes clinic at the University of Minnesota (UMN) in order to gauge their future risk.

It has been shown that cultural factors affect diabetes management in immigrant populations [22]. Understanding the specific cultural views towards diabetes, the perception of this condition in the Somali community, and attitudes towards treatment with medications versus folk/spiritual medicine, has the potential to significantly influence outcomes through partnership and compliance

with management. This study tapped into this aspect through developing and administering a survey from which responses could be used to customize and target education, an integral part of diabetes management, to address myths and common misconceptions, develop educational tools that are population-relevant, practical and culturally-sensitive, and to consolidate trust in the medical team, and improve adherence to management.

This dissertation includes two submitted manuscripts. The first describes the HLA types and diabetes autoantibody status of a group of Somali children with T1D, while the second compares diabetes control in a group of Somali children with T1D to non-Somali children with T1D who are followed in the same clinic, and describes their cultural beliefs in relation to diabetes.

Chapter Two: Predominance of DR3 in Somali Children with Type 1 Diabetes in the Twin Cities, Minnesota

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Summary

Background: Minnesota is home to the largest Somali population in the US, and pediatric diabetes teams are seeing increasing numbers of Somali children with diabetes.

Objective: To assess the immune and genetic basis of type 1 diabetes in Somali children in the Twin Cities, Minnesota.

Methods: Twenty-seven Somali children ≤19 years treated for diabetes at the University of Minnesota Children's Hospital and Children's Hospitals and Clinics of Minnesota underwent analysis of HLA alleles (n=26) and diabetes autoantibodies (GAD65, mIAA/IA, IA-2, ZnT8; n=27). Anti-transglutaminase antibodies (TG) for celiac disease were also measured.

Results: In Somali children aged 12±5 years (33% female, disease duration 4±3 years), the most common HLA phenotype was DR3 (92% of subjects, allele frequency 63%), followed by DR13 (27%, allele frequency 14%). There was a relatively low frequency of DR4 (15%, allele frequency 8%). All 27 participants had positive elevation of at least one diabetes autoantibody.
All were on insulin, and insulin antibodies were positive in 93%. Excluding insulin antibodies, 19 (70%) were positive for at least one other diabetes autoantibody; 37% had 1 autoantibody, 22% had 2, and 11% had 3. GAD65 antibodies were found in 56% of subjects, IA-2 in 33%, and ZnT8 in 22%. Three (11%) were TG positive.

Conclusion: The autoantibody and HLA profiles of Somali children with diabetes are consistent with autoimmune type 1 diabetes (T1D). Their HLA profile is unique with an exceptionally high prevalence of DR3 alleles and relative paucity of DR4 alleles compared to African Americans with T1D.

Background

The East African coastal country of Somalia has experienced more than two decades of brutal civil war. Since the early 1990's, refugees have settled in other East African countries, Europe, Canada and the United States (US). A small group of Somali refugees was initially assigned to live in Minnesota by the US State Department working with local relief agencies; friends and relatives soon followed when word about the favorable job market and religious tolerance in Minnesota spread [23]. Minnesota now has the largest population of Somalis in the US, with the majority of immigrants living in the adjoining cities of Minneapolis and St. Paul ("the Twin Cities") [2]. The 2011 United States Census Bureau estimates that there are more than 32,000 people of Somali ancestry in Minnesota, including both those born in Somalia and their descendants [2], though this is widely believed to be an underestimation.

Pediatric endocrinologists in the Twin Cities have observed relatively high numbers of Somali patients with type 1 diabetes (T1D). Given the paucity of information in the literature describing the genetic and autoimmune profiles of T1D in Somalis, the following study was undertaken in Somali children to evaluate the autoantibody profile and HLA genotypes typically associated with T1D. We hypothesized that this population might have a unique HLA phenotype compared to other ethnic populations in the United States.

Research Design and Methods

Subjects

Somali children ≤19 years with T1D seen in pediatric diabetes clinics at the University of Minnesota Children's Hospital (UMN) from January 1st, 2012 to January 31st, 2014 and at Children's Hospitals and Clinics of Minnesota (CHCM) from January 1, 2013- October 31, 2013 were invited to participate. Peripheral blood samples were collected and serum for antibodies and

buffy coats for HLA were frozen and sent for analysis to the Eisenbarth Laboratory at the Barbara Davis Center for Childhood Diabetes (BDC, Denver, Colorado). All participants gave informed consent/assent using an IRB approved protocol with the assistance of a Somali interpreter as needed, and consent forms were provided in English and in Somali based on participants' preference.

Comparison data from African American pediatric patients with T1D were obtained from new-onset diabetes studies and population studies collected at BDC [24-27] and from published data [28]. The frequency of high risk T1D alleles in the Minnesota Somali cohort was compared to 12 Somali children with T1D in Finland [15], 27 African American children with T1D at the Barbara Davis Center (BDC) [27], and a large population of African Americans (n=772) with T1D.

Analysis

The Eisenbarth Laboratory serves as the autoantibody/HLA reference laboratory for several large national studies including Type 1 Diabetes TrialNet and the Immune Tolerance Network. Insulin autoantibodies/antibodies (mIAA/IA) [29] were measured by radioimmunoassay, and islet antigen 2 (IA-2) [30], glutamic acid decarboxylase (GAD65) [30], and zinc transporter 8 (ZnT8) [25, 26] autoantibodies were measured by radioimmunoassay utilizing *in vitro* transcribed/translated proteins. Anti-transglutaminase antibodies (TG) for celiac disease were measured by radioimmunoassay. HLA Class II DRB1, DQA1 and DQB1 alleles were determined using luminex xMAP technology (Luminex, Austin, TX). SSO microspheres used for HLA allele typing were obtained from One Lambda, Inc., Canoga Park, CA.

Results

Subjects

At UMN, 22 Somali children and youth with T1D were followed in pediatric diabetes clinic during the study period, twenty of whom participated. One of the 2 non-participating patients was excluded because of a history of a donor-unrelated cord blood transplant for aplastic anemia and a recent history of multiple blood transfusions. The second non-participant was a female who was lost to follow up. An additional 5 subjects were recruited from CHCM, from about 50 Somali children and youth who were seen in diabetes clinic during the study period. All subjects were on basal-bolus insulin therapy either by multiple daily injections or by insulin pump.

Table 2.1. Subject Characteristics.

Patient No.	Age (yr)	Sex	Duration T1D (yrs)	Age T1D Onset (yr)	Birth Country	BMI z-score	Somali Clan Mother	Somali Clan Father
1	13	F	9.3	3	US	1.15	Ogaadeen	Ogaadeen
2	16	F	5.3	11	US	1.68	Daarood	Daarood
3	19	M	3.6	15	Ethiopia	-0.86	Isaaq	Ciise (Dir)
4	18	M	7	11	Kenya	-1.98	Hawiye	Hawiye
5	10	M	7.2	3	US	0.82	--	--
6	12	M	5.3	6	US	-0.54	Hawiye	Hawiye
7	15	M	2.4	13	US	-0.10	Majeerteen	Majeerteen
8	2	M	0.7	1	US	0.56	--	--
9	17	M	2.5	14	US	1.43	Dir	Daarood
10	7	F	2.3	5	US	0.88	Slaban (Suleman) (Hawiye)	Ogaadeen
11	5	F	1	4	US	0.41	Ogaadeen	Ogaadeen
12	16	M	4	12	US	1.02	Digil(Tumi)	Majeerteen
13	3	M	1.3	2	US	1.22	Mejeerteen	Majeerteen
14	15	M	4	11	US	-2.56	Hawiye	Hawiye
15	15	M	13	3	US	1.06	Majeerteen	Majeerteen
16	10	F	1.9	8	US	0.94	Hawiye	Hawiye
17	10	F	3.9	6	US	1.26	Warsangali	Warsangali
18	13	M	6.4	7	US	1.55	Ogaadeen	Ogaadeen
19	8	F	3.1	4	US	0.52	--	--
20	17	F	6.6	10	Kenya	0.19	--	--
21	8	M	2.5	5	US	-1.53	Warsangali	Air(Hawiye
22	11	M	1	10	US	0.9	--	--
23	3	M	2.6	0.5	US	0.2	Gudarbiise (Dir)	Ciise (Dir)
24	13	M	0.15	12	US	1.15	Ogaadeen	Ogaadeen
25	17	M	10.9	6	Kenya	0.23	Ogaadeen	Majeerteen
26	11	F	0.5	10	US	1.57	Majeerteen	Majeerteen
27	3	M	2.3	1	US	1.16	Ogaadeen	Ogaadeen

Subject characteristics are summarized in Table 2.1. Mean age at time of enrollment was 12.3±5.0 years old with a mean age at onset of diabetes of 7.0±4.4 years. Sixty-seven percent were male. Subjects were well nourished, with a BMI z-score of 0.46±1.1. All but 4 participants (85%) were born in the US. The 4 non-US-born participants were born in Kenya (n=3) and Ethiopia (n=1). The majority of patients participating in this study were from the Daarood clan: 16 of them (59%) had at least one parent from the Daarood clan or one of its subclans (Majeerteen, Ogaadeen, and Warsangali).

Autoantibody Profiles

All 27 patients had positive titers reflecting elevation of at least one diabetes autoantibody (Table 2.2). Insulin administration itself can induce insulin antibodies and, predictably, insulin autoantibodies/antibodies (mIAA/IA) were positive in 93% (n=25); the two subjects without mIAA/IA were positive for other diabetes autoantibodies. Excluding insulin antibodies, 19 of 27 (70%) participants were positive for at least one diabetes autoantibody; 37% (n=10) of subjects had 1 autoantibody, 22% (n=6) had 2, and 11% (n=3) had 3. GAD65 antibodies were found in 56% of subjects, IA-2 in 33%, and ZnT8 in 22%. Thus, the autoantibody profiles in these patients were consistent with autoimmune type 1 diabetes.

Anti-transglutaminase (TG) antibodies (positive in autoimmune celiac disease which is found in about 3% of diabetes) were positive in 3 participants (11%). One had biopsy-proven celiac disease but was having difficulty following a gluten-free diet (subject #3), while the other two had not been previously identified as potentially having celiac disease.

HLA Typing

HLA results are depicted in Table 2.2. Ninety-two percent of participants had at least one DR3 allele, and 9 subjects (35%) were DR3 homozygous. After DR3, the most common DR phenotype was DR13, with 7 (27%) subjects carrying at least 1 DR13 allele. Only 4 (15%) subjects had at least one DR4 allele, and none were DR4 homozygous. Three of these subjects (12%) were DR3/DR4. Two subjects (8%) carried at least one DR1 allele and one was homozygous.

Table 2.3 compares the Minnesota Somali pediatric diabetes population to other populations. A group of 12 Finnish Somali children with diabetes also demonstrated a relatively

high allele frequency of DR3 (38% vs 63% in our population), as well as prominence of DR13 and a relatively low frequency of DR4 alleles. In contrast, the African American T1D patients studied at BDC had higher DR13 (37%), followed by DR3 (33%) and DR4 (26%) phenotype frequencies. Similarly, in the larger cohort of US African American children, DR3 haplotype frequency was lower than in our Somali population (26%).

Table 2.2. HLA type, diabetes autoantibody titers, and celiac autoantibody titers. These samples were analyzed by the lunimex specific oligonucleotide (SSO) method, which is able to distinguish between more alleles than the previous method of Dynal sequence SSO: *would be listed as DQA1*0301 by Dynal, **would be listed as DQB*0201 by Dynal. Normal cut-off values for autoantibody titers are GAD65=20, IA-2=5, mIAA/IA=0.01, ZnT8=0.02, TG=0.05. Grey boxes indicate positive antibody titers.

	HLA Haplotypes							Diabetes Autoantibodies				
Pt	**DR**	**DRB_1**	**DQA1_1**	**DQB1_1**	**DRB_2**	**DQA1_2**	**DQB1_2**	**GAD65**	**IA-2**	**mIA**	**ZnT8**	**TG**
1	DR3/ DR1	03:01	05:01	02:01	01:02	01:01	05:01	267	0	0.097	0.006	0.004
2	DR3/ DR4	03:01	05:01	02:01	04:01	03:02*	03:02	0	23	0.709	0.008	0.005
3	DR3/ DR4	03:01	05:01	02:01	04:05	03:02*	02:02**	25	0	0.036	0.005	0.259
4	DR3/DR4	03:01	05:01	02:01	04:05	03:03	03:02	0	17	0.022	-0.001	0.003
5	DR3/ DR3	03:01	05:01	02:01	03:01	05:01	02:01	11	4	0.087	0.004	0.008
6	DR3/ DR3	03:01	05:01	02:01	03:01	05:01	02:01	7	2	0.681	0.011	0.014
7	DR3/ DR3	03:01	05:01	02:01	03:01	05:01	02:01	182	429	0.436	0.142	0.003
8	DR3/ DR3	03:01	05:01	02:01	03:01	05:01	02:01	435	3	0.003	0.001	0.017
9	DR3/ DR3	03:01	05:01	02:01	03:01	05:01	02:01	541	0	0.169	0.161	0.011
10	DR3/ DR3	03:01	05:01	02:01	0301	05:01	02:01	17	0		0.002	0.002

11	DR3/DR3	03:01	05:01	02:01	03:01	05:01	02:01	29	0	0.597	-0.002	0.062
12	DR3/DR3	03:01	05:01	02:01	03:01	05:01	02:01	636	0	0.118	-0.002	-0.001
13	DR3/DR3	03:01	05:01	02:01	03:01	05:01	02:01	162	0	0.366	0.011	-0.001
14	DR3/DR13	03:01	05:01	02:01	13:02	01:02	06:09	0	14	0.052	0.001	-0.006
15	DR3/DR13	03:01	05:01	02:01	13:02	01:02	06:04	0	1	0.045	0.007	-0.001
16	DR3/DR13	03:01	05:01	02:01	13:02	01:02	06:04	903	78	0.051	0.234	0.012
17	DR3/DR13	03:01	05:01	02:01	13:02	01:02	06:04	34	69	0.012	0.008	0.008
18	DR3/DR13	03:01	05:01	02:01	13:02	01:02	06:04	2	0	0.546	0.007	-0.01
19	DR3/DR13	03:01	05:01	02:01	13:02	01:02	06:04	22	2	0.139	0.001	0.005
20	DR3/ DR8	03:01	05:01	02:01	08:04	05:01	03:01	122	1	0.334	0.012	0.154
21	DR3/ DR8	03:01	05:01	02:01	08:04	05:01	03:01	6	1	0.649	0.008	0.009
22	DR3/DR8	03:01	05:01	02:01	08:04	04:01	04:02	1	285	0.253	0.381	-0.001
23	DR3/ DR9	03:01	05:01	02:01	09:01	03:02*	03:02	1090	0	4.369	0.006	0.004
24	DR3/DR10	03:01	05:01	02:01	10:01	01:01	05:01	92	180	0.003	0.004	0.008
25	DR4/DR13	04:05	03:01	02:02**	13:02	01:02	06:09	2	0	0.011	0.002	-0.01
26	DR1/ DR1	01:02	01:01	05:01	01:02	01:01	05:01	428	387	0.012	0.075	0.016
27	---	---	---	---	---	---	---	7	0	0.278	0	0.013

Table 2.3. Comparison of high-risk DR alleles in 26 Minnesota Somali children with T1D (MN), 12 Finnish Somali children with T1D ([15]), 27 African American children with T1D at the Barbara Davis Center (AA[1]), and 722 African American children with T1D from published data (AA[2]). Data are presented as number within the population and (frequency within the population).

	MN	FINN	AA[1]	AA[2]
DR3 phenotype	24/26 (92%)	7/12 (58%)	9/27 (33%)	--
DR3 allele	33/52 (63%)	9/24 (38%)	12/54 (22%)	398/1544 (26%)
DR3/DR3	9/26 (35%)	2/12 (17%)	3/27(11%)	69/772 (9%)
DR4 phenotype	4/26 (15%)	2/12 (17%)	7/27 (26%)	--
DR4 allele	4/52 (8%)	3/24 (13%)	7/54 (13%)	350/1544 (23%)
DR4/DR4	0/26 (0%)	1/12 (10%)	0/27 (0%)	18/772 (2%)
DR4/DR3	3/26 (12%)	0/12 (0%)	3/27 (11%)	
DR13 phenotype	7/26 (27%)	4/12 (33%)	10/27 (37%)	--
DR13 allele	7/52 (14%)	4/24 (17%)	10/54 (19%)	70/1544 (5%)
DR1 phenotype	2/26 (8%)	4/12 (33%)	4/27 (15%)	--
DR1 allele	3/52 (6%)	5/24 (21%)	5/54 (9%)	83/1544 (5%)
DR9 phenotype	1/26 (4%)	0/12 (0%)	4/27 (15%)	--
DR9 allele	1/52 (2%)	0/24 (0%)	4/54 (7%)	142/1544 (9%)

Discussion

Our analysis demonstrates that the autoantibody and HLA profiles of Somali children with diabetes are consistent with autoimmune type 1 diabetes. Their HLA profile is unique, however, with an exceptionally high prevalence of DR3 alleles, a high prevalence of DR13 and DR1 alleles, and relative paucity of DR4 alleles compared to established profiles of US African American children.

HLA DR3 and DR4 are well known to be associated with the highest risk for developing T1D [31], but the clear preponderance of DR3 in our Somali population is unusual. While DR3 may indeed be a particularly high risk diabetes allele for Somalis, an alternative explanation is that DR3 may be common overall in Somali immigrants, whether or not diabetes is present, in what is likely a relatively inbred population. Somalis are organized into patrilineal clan groupings. These are very important social units, and clan associations have undoubtedly had a major influence on both exile and immigration patterns. No official information exists on the clan background of Minnesota's Somalis, but over two-thirds of Somali patients participating in the current study (including the two who did not carry DR3 alleles) were from the Daarood clan. Currently, little information is available regarding the background HLA phenotype in the general Somali population. In a previous analysis of 76 Somalis living in England, HLA genotypes with the highest frequencies were DR13, DR17, DR8 and DR1; interestingly, DR3 was not identified [32]. The HLA pattern in the English cohort was felt to be more related to typical Arab HLA class I and class II antigens than to that of African populations. This conclusion was consistent with Y chromosome and mitochondrial DNA analyses demonstrating that Somalis are more closely related to Ethiopians, Sudanese, Egyptians, and North African Arabs than to other African populations [33, 34]. Another reason the Somali genotype may differ from that of African Americans is that the Somali community remains relatively ethnically homogeneous and lacks the significant genetic mixing that has occurred between African Americans and Caucasians since Africans were first brought to the Americas several centuries ago.

Almost all of the Somali children with diabetes were born in the US which begs the question of whether the disease is triggered more often in a Western environment compared to

their native country. Unfortunately, the incidence and prevalence of pediatric diabetes has not been established in Somalia. Until the last few years, pediatric endocrinologists were rare in sub-Saharan Africa, and most clinics were not equipped to perform blood glucose testing. Children with diabetes usually died without ever receiving a correct diagnosis. Even when a diagnosis was made, insulin therapy was not reliably available and life expectancy was short, making accurate assessments of diabetes prevalence nearly impossible. A pediatric endocrinology fellowship training program in Kenya sponsored since 2008 by the European Society for Pediatric Endocrinology (ESPE) and the International Society for Pediatric and Adolescent Diabetes (ISPAD), has now trained dozens of African pediatric endocrinologists, creating a dramatic improvement in recognition of diabetes as a disease entity. This, together with greater accessibility of insulin (and to a lesser extent test strips) through international relief organizations such as Life for a Child and pharmaceutical company charitable programs, has significantly improved the situation for children with diabetes in Africa. With increased disease recognition and better care, the prevalence of childhood diabetes is rapidly increasing [35]. Unfortunately, these changes have not yet reached Somalia, where near total social disintegration exists due to decades of war. Until Somalia's political situation stabilizes, accurate medical diagnoses data on the prevalence of childhood diabetes will remain elusive.

Similar to Minnesota, Finland has also experienced a large Somali immigration. HLA analysis of 12 young diabetic patients was comparable with the Minnesota findings, with an unusually high frequency of DR3, high frequencies of DR13 and DR1, and low DR4. Interestingly, the prevalence of T1D in Somali children was equal to that of all Finnish children, generally considered the highest in the world. The total population of Somali children in Minnesota is estimated from census data to be about 17,000 children [36]. Most children with diabetes in Minnesota, even from the outlying areas, are seen by 4 pediatric endocrinology clinics in the Twin Cities and Rochester. These 4 together report about 80 Somali T1D patients (personal communication). If approximately 80 of 17,000 Somali children have diabetes, the estimated prevalence of diabetes in Somali children is about 1/250 children, which is higher than the general population estimated prevalence of 1/400 to 1/500 children with diabetes in Minnesota [37, 38] and the US [38]. However, state census data probably underestimate the total number of Somalis in Minnesota and thus the true number is probably more similar to that of the general population. Further epidemiological studies are needed to generate a more accurate estimate of prevalence of T1D in Somali children in Minnesota.

Although our analysis describes the largest cohort of Somali children with T1D to date, a limitation of this study remains the relatively small subject number, which can lead to erroneous conclusions in genetic analyses. Nevertheless, it is reassuring that the Minnesota and Finnish studies largely agree with respect to HLA type. An additional limitation is the lack of genetic background information on the general Somali population; efforts are planned to perform HLA typing in non-diabetic Somalis in Minnesota.

In conclusion, diabetes appears to be as common in Somali children as in the general US population, and is clearly autoimmune in origin. In contrast to African American populations, DR3 genotype appears to be particularly preponderant, and DR4 appears to be of less importance in Somalis with T1D.

Chapter Three: Understanding Cultural Beliefs in Families of Somali Children with Diabetes in Minnesota

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Summary

Objective: Describe cultural beliefs related to diabetes in Minnesota Somali children with type 1 diabetes (T1D), and compare their diabetes control to that of T1D non-Somali children.

Methods: A cross-sectional study involving Somali children ≤19 years with T1D at the University of Minnesota Children's Hospital and Children's Hospitals and Clinics of Minnesota. A survey was administered to parents of all participants and to children aged ≥12 years. Demographic and clinical data were collected by history and from medical records.

Results: Twenty-five Somali children participated, with 24 parent-child pairs (2 siblings). Mean participant age was 12.2±5.2 (36% female). Seventy-one percent of parents indicated the child was "the same as before" other than having to do diabetes cares. Families were coping well, and the child was not treated differently than siblings. Performance of routine medical cares was described as the hardest part about having diabetes, but this was not related to conflicts with traditional culture or religion. One notable exception was difficulty finding resources to help with performing carbohydrate counting on traditional Somali foods. Respondents were appreciative of the education provided by the diabetes team. Less than 10% used herbal supplements in addition to insulin. Mean HbA1c in Somali children was higher than the overall pediatric clinic average, 9.5±1.6% vs 8.8±1.6 (p =0.01). The difference was largely due to adolescent patients.

Conclusion: The majority of Somali families cope well with diabetes and have a positive attitude towards diabetes education and the diabetes team. Glycemic control in adolescents is worse than that of non-Somali peers. There is a need for culture-specific dietary instruction materials.

Background

Successful management of a chronic disease such as T1D requires that patients and families perform complicated tasks multiple times a day. To do this, they must understand what should be done and why, accept that the tasks are necessary, and learn how to integrate these activities into everyday life. In immigrant populations, the social and religious aspects of their unique cultures can influence acceptance of these crucial components of chronic disease management [22]. Although healthcare workers may acknowledge the potential impact of culture and religion, a knowledge gap of how to best tailor education and management approaches to the needs of specific populations often exists.

Minnesota is home to the largest Somali population in the US [1]. A reported 32,000 Somalis live in the state, although this may be an underestimation [9]. The vast majority resettled in Minnesota in the 1990's and early 2000's as refugees fleeing the civil war that erupted in their home country of Somalia. This shift in the state population demography over the past decades is reflected in the diversity of patient ethnicities seeking health care. Childhood T1D has emerged as one of the challenging problems this population is facing in Minnesota and elsewhere [15]. Raising awareness among healthcare providers about the cultural nuances of Somalis and understanding their perception of disease, the difficulties they face, and their needs, may help in the development of culturally-appropriate plans for overcoming the hurdles confronting this population and provide them with a better patient experience and improved diabetes control [39, 40]. This knowledge could facilitate bridging gaps between the Somali community and the healthcare system. Given the paucity of data describing the Somali community's stance on modern medicine and its relation to their cultural and/or religious beliefs, we conducted a pilot survey of families of Somali children with T1D. The ultimate goal is to improve diabetes control in the Somali population, and provide a better patient experience in managing this chronic condition.

Study Design and Methods

Participants

Pediatric patients aged ≤19 years of Somali ancestry with T1D living in the greater Minneapolis-St. Paul-Bloomington metro area, Minnesota, followed at the University of Minnesota (UMN) Pediatric Diabetes Clinic and at Children's Hospitals and Clinics of Minnesota (CHCM) were identified from January 1st, 2012- January 31st, 2014. Recruitment took place with the assistance of a Somali interpreter and an undergraduate Somali student at UMN. Demographic data were collected via history and the medical record, including birth place, place of diagnosis (US, Somalia, Kenyan or Ethiopian refugee camp, other) and percent of lifetime lived in the US. Clinical information obtained by history included family history of diabetes, date of diagnosis, number of hospitalizations for diabetic ketoacidosis, and number episodes of severe hypoglycemia (seizure, unconsciousness). Clinical information obtained from the electronic medical record included current insulin regimen, insulin dose, and most recent height and weight. Hemoglobin A1c (HbA1c) levels for each participant were averaged over the evaluation years; HbA1c values in the first 6 months following diabetes diagnosis were not included in analyses. Mean annual HbA1c value was calculated for the non-Somali pediatric diabetes clinic T1D patient population followed at UMN during the study years (n=351). The study was approved by the UMN and CHCM Institutional Review Boards. Written informed consent was obtained from parents/guardians (in English or Somali, based on participant preference) and assent from participating children through an interpreter.

Surveys

Members of the pediatric diabetes team together with a Somali interpreter constructed a survey containing open- and closed-ended questions examining cultural and religious beliefs related to diabetes. Questions for the survey were based on observations of parental concerns and or common misconceptions that had consistently emerged during diabetes clinic visits. Surveys were available both in English and Somali, depending on respondent preference. The parent(s) of each participant took the survey (19 mothers and 5 fathers). Children aged ≥12 years were asked to fill out the same survey as their parents. Eight of the 14 questions were multiple-choice with more than one answer, where respondents were asked to select all that applied. Additionally, each

of these questions had an option for "other", allowing respondents to write their own response if none of the options seemed relevant. The remaining 6 questions were open-ended with no answers provided.

Questions were filled out at the time of recruitment after informed consent was obtained with the assistance of a Somali interpreter, as needed.

Statistical Analyses

Data were analyzed using SAS version 9.3 (SAS Institute Inc., Cary, NC). Descriptive statistics are primarily presented as mean±standard deviation (SD). HbA1c averages were compared between patients of Somali origin who participated in the study and those of the overall T1D pediatric population in the UMN clinic using Student's t-test. P-values <0.05 were considered statistically significant.

Several questions in the survey allowed for more than one answer including multiple-choice questions. The proportion of participants who answered a question positively (or optimistically) versus the number who had a negative response to that question was determined among parents and children. For open-ended questions, results are displayed as frequency of each of the responses provided.

Results

Subjects

Twenty-three children of Somali origin age ≤19 years were followed at UMN during the study period. Of these, 20 (87%) consented to participate in the study but two did not complete the surveys, leaving a total of 18 participants from UMN. Seven patients followed at CHCM were recruited to participate. Participant characteristics are detailed in Table 3.1. Four participants (16%) were born outside of the US in African refugee camps (1 in Ethiopia and 3 in Kenya). All but one, were diagnosed with T1D in the US (96%). Mean BMI percentile was 62±30% (range 6->99%). Twelve percent (n=3) of participants were overweight (BMI ≥ 85^{th} < 95th percentile) and 1 participant was obese (BMI ≥95th percentile) for age and gender.

Table 3.1. Characteristics of 25 Somali children with T1D age ≤19 years. * NA= Not available

Variable	Mean ± SD or N (%)
Age, yrs	12.2 ± 5.2
Female gender	9 (36)
Age at diagnosis, yrs	6.8 ± 4.4
Duration of diabetes, yrs	5.3 ± 3.6
US-born	21 (84)
Percent of lifetime lived in US	91 ± 25
Family history of diabetes (Yes/No/*NA)	21/3/1
Prior DKA (Yes/No/*NA)	13/8/4
Previous Severe hypoglycemia (Yes/No/*NA)	4/20/1
Average insulin dose, unit/kg/day	0.75 ± 0.3
Hemoglobin A1c, %	9.5 ± 1.6
BMI, kg/m²	19.8 ± 3.7
BMI z-score	0.47 ± 1.1

Survey Results

Twenty-four surveys were completed by parents of 25 children, including 2 siblings. Twelve children who were ≥12 years old also participated. Some of the questions were left unanswered by participants. This was especially true for the open-ended questions. Overall, the survey responses indicated a positive and optimistic attitude about the impact of diabetes on the child and the family. They appreciated the information and education provided by the pediatric diabetes team (Table 3.2).

Table 3.2. Summary of Survey Results. N=24 parent respondents (5 fathers and 19 mothers) and 12 children age 12-19 years with diabetes. The survey included 8 multiple choice questions (with an option for "other" if none of the responses applied), and 6 free-response open-ended questions. Not all subjects answered all questions.

Multiple Choice Questions	**Parents, N (%)**	**Patients N (%)**
1. What does having diabetes mean for your child now?		
Positive: child has to do diabetes cares but is otherwise the same as before	17 (71)	8 (67)
Negative: child is sick, has to stay home	7 (29)	4 (33)
2. How has the diagnosis of diabetes affected your child?		
Positive: no change	13 (57)	5 (45)
Negative: perceives self as "sick", difficulty fitting in with peers, embarrassed	10 (43)	6 (55)
3. What concerns do you have about your child's future?		
Positive: no concerns	13 (57)	6 (55)
Negative: difficulty finding a partner or job, fertility, future diabetes complications	10 (43)	5 (45)
4. What impact does having a child with diabetes have on your family?		
Positive: no change, family copes well	19 (79)	10 (83)
Negative: disrupts family life, hard on the other children in family, Mom feels guilty	5 (21)	2 (17)
5. How do you treat your child with diabetes compared to your other children?		
Positive: no different except for diabetes specific cares	17 (71)	8 (67)
Negative: child is "fragile", different discipline compared to siblings	7 (29)	4 (33)

6. How do you think your Somali community perceives children with diabetes?		
Positive: Not any different from other children	14 (58)	9 (75)
Negative: disabled, sick, abnormal	10 (42)	3 (25)
7. Could your child's diabetes have been prevented?		
Positive: No, not sure	22 (92)	11 (92)
Negative: Yes	2 (8)	1 (8)
8. What remedies have you used alongside insulin to treat diabetes?		
Positive: None, prayer	21 (91)	11 (92)
Negative: Herbal supplements	2 (9)	1 (8)

Open Ended Questions--Free responses, subjects may have more than 1 answer	**Parents, N**	**Children, N**
9. Why do you think your child got diabetes?		
Don't know	4	0
God's will	4	2
Exposure (environment or medications)	2	0
Bad eating habits	1	2
Illness or infection	1	1
Got it from someone else	1	4
Pancreas stopped working	0	1
Parent "not there for child"	1	0
10. What is the hardest part about having a child with diabetes?		
Nothing	1	1
Counting carbs	1	0
Checking glucose level and giving insulin on time	6	4
Managing sick days	0	1
Lifestyle changes	3	4
Worrying about child's health	1	2
11. What part of your child's current treatment is hard to fit into your traditional culture or religion?		
None	9	9
Difficulty with Ramadan	0	2
Other people think it can be cured	1	0
Eating Somali food	2	0
Going to the doctor often	1	0

12. What has your medical team done for you/your child that has been helpful?		
Provided information/education	7	1
Managed blood sugars and insulin	6	5
Helped with lifetime struggle	1	3
Group meeting with the family	1	0
Learn the outcome of this study	1	0
13. What do you wish your medical team would do to further help you/your child?		
Nothing, they already do everything they can	2	4
Understand Somali diet	4	0
Find a cure for diabetes	4	1
Find a new treatment that tis not an injection	1	0
Emotional support	2	1
Continue to provide the best treatment, follow-up and education	2	2
14. What would be helpful for the medical team to know about your culture and childhood diabetes?		
Nothing	2	3
Concerns about fasting in the future	1	1
Somali food-specific carb counting	2	3
Female patients feel more comfortable with female providers	1	0
Things that happen in life are God's will	1	0
My child is not any different from other kids	1	0
Diabetes in kids is not known to our community	1	0
We trust the medical team	1	1
Exercise and diet alone are sufficient	1	1
Learning about diabetes resources available to our community	0	1

With regards to the effect of diabetes on the child, more than two-thirds of respondents indicated the child was "the same as before" other than having to do diabetes cares. However, in response to a separate question, 43% of parents and 55% of children reported that the child perceived him or herself as sick, had difficulty fitting in with peers, or was embarrassed by the disease. The most common concern expressed about the child's future was risk of diabetes complications.

Seventy-nine percent of parents and 83% of children felt the family was coping well with the diagnosis of diabetes, and for the most part reported that the child with diabetes was not treated differently than siblings. Performance of routine medical care such as counting carbohydrates, checking glucose levels, and giving insulin was described as the hardest part about having diabetes.

Forty-two percent of parents and 25% of children had concerns about how the Somali community perceives children with diabetes. However, they mostly did not feel that diabetes treatment was hard to fit into their traditional culture or religion. One exception was difficulty performing carbohydrate counting on foods in the traditional Somali diet, which was mentioned several times.

Almost all parents and children answered that T1D could not have been prevented, although some of the answers in the open-ended questions suggested that some of them suspected preventable etiologies such as contagious illness, diet, or that the parent was at fault. Less than 10% used herbal supplements in addition to insulin, and these were primarily honey and garlic.

Diabetes Management and Metabolic Control

The majority of participants (67%) were on a regimen consisting of multiple daily injections with a long-acting basal insulin and a rapid-acting insulin analog. The remaining participants used an insulin pump. The average insulin dose was 0.75 ± 0.3 units/kg/day (range 0.18-1.35).

HbA1c data were normally distributed. The mean HbA1c in the total group was 9.5±1.6% (range 6.1-12.9%). In contrast, the HbA1c was 8.8±1.6% (range 5.2-15%) for non-Somali patients age ≤19 years (p =0.01) (Figure 3.1).

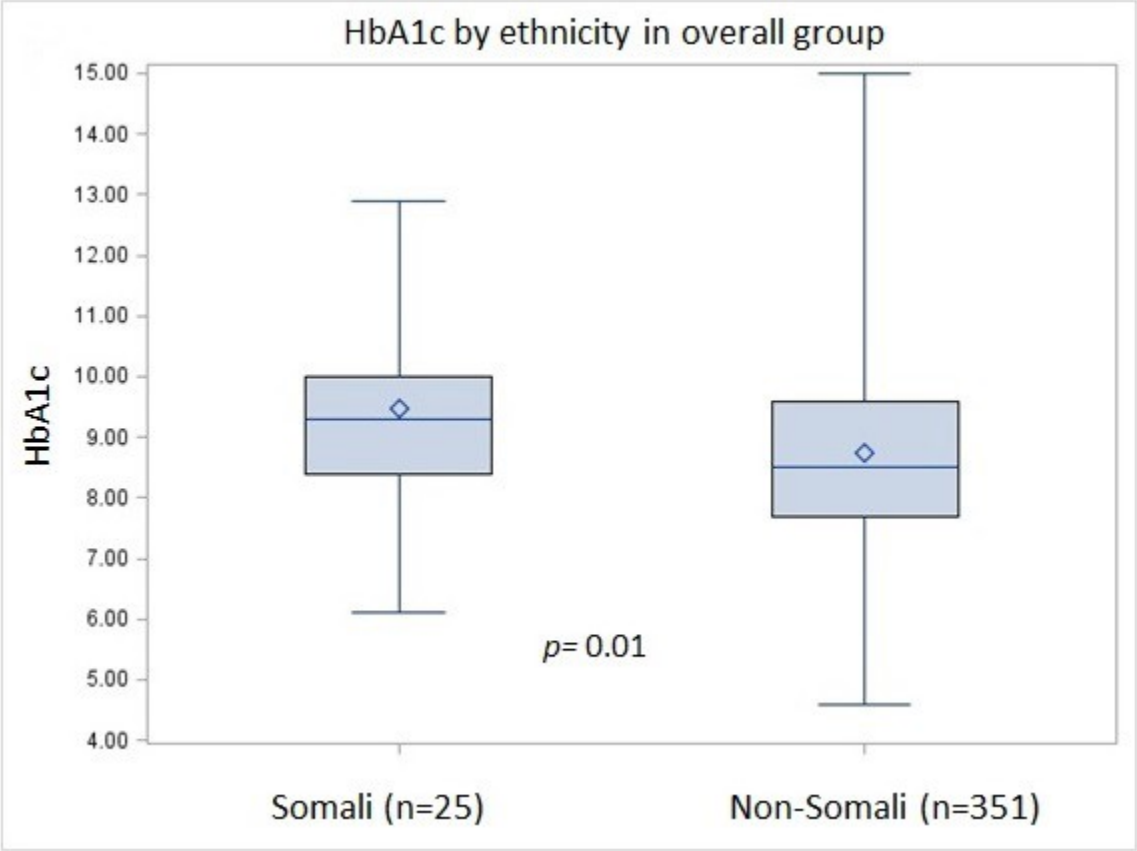

Figure 3.1. HbA1c levels in Somali and non-Somali patients with type 1 diabetes in the total cohort aged ≤19 years.

When analyzed by age group, amongst children <10 years of age there was no difference in HbA1c levels between the Somali children (n=7) and the clinic cohort (n= 59) (8.8±0.8% vs 8.5±1.1% respectively; (p =0.4) (Figure 3.2). All 7 Somali children <10 years had an HbA1c above the ADA target goal [41] for age compared to 86% of the clinic population.

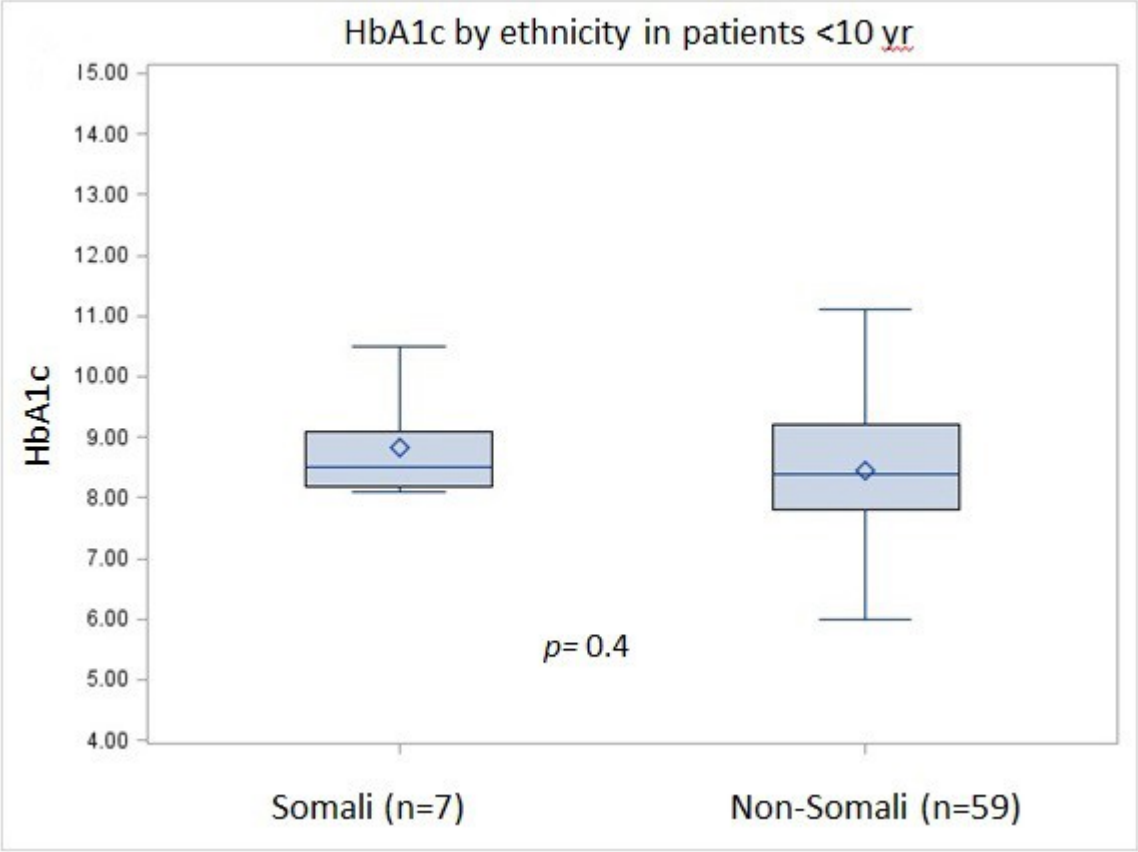

Figure 3.2. HbA1c levels in Somali and non-Somali patients with type 1 diabetes <10 years of age.

In contrast, the average HbA1c level in patients of Somali origin age 10-19 years was 9.7±1.7% (n=18) which was significantly greater than the average HbA1c of 8.8±1.7% in their non-Somali peers (n=292, p =0.02) (Figure 3.3). Almost all (94%) Somali adolescent patients had an HbA1c above the ADA target threshold [41] for this age group compared to 80% of the clinic population.

Two of the 3 Somali patients followed at the UM who chose not to participate reached their 19th birthday during the study period and the mean age was 19.8 ±1.3 years for all 3 patients at the end of the study. In these non-participants, mean HbA1c was 8.6±3.1%.

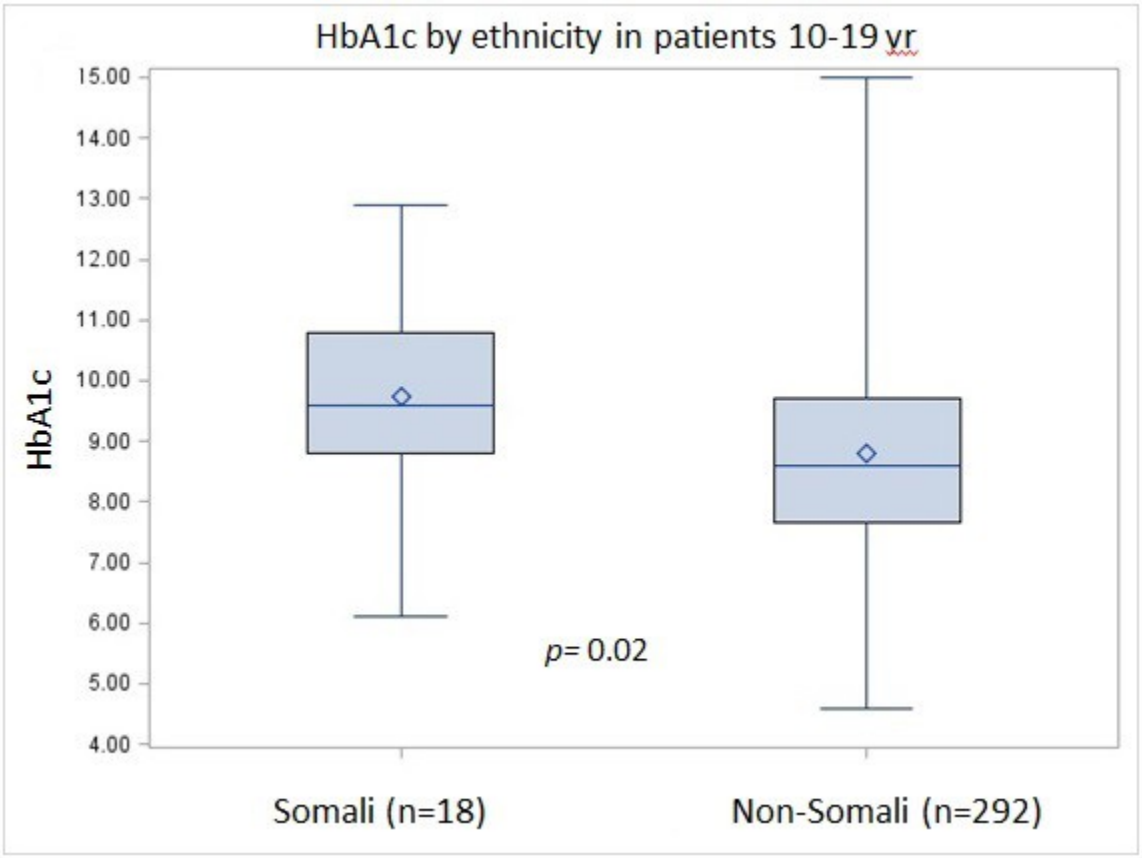

Figure 3.3. HbA1c levels in Somali and non-Somali patients with type 1 diabetes 10-19 years of age.

Discussion

To our knowledge, this is the first published report describing the cultural and religious beliefs of Somali parents and children towards pediatric T1D. This study suggests that Somalis are largely appreciative of the diabetes education and support they receive from the pediatric diabetes team. Families generally cope well with the diagnosis, and do not report stigmatization of the child with diabetes. However, diabetes control, especially among adolescents, is worse than that of their peers of non-Somali origin.

Prior to the current wave of Somali immigrants, in the 1980's and 1990's the Minnesota medical system had the experience of working with a large influx of Southeast Asian immigrants, who became known for their distrust of the medical establishment and their reliance on traditional healers [42, 43]. In contrast, the latest group of immigrants to Minnesota, the Somalis, appear to be far more accepting of modern medicine. This may be at least in part explained by the common Somali religious belief that everything that happens is God's will and is planned by God and, therefore, cannot be prevented. Similarly, this take on life may explain why a large portion of survey respondents stated they had no concerns about their child's future. When parents were asked specifically about whether they felt finding a marriage partner or fertility would be a potential future problem for their child, the response was almost always "no", especially when the child was a male. While these parents may truly not have these concerns, it is also possible that they are amongst the "silent worries" described (in a different context) by Pavlish et al as topics that cannot be talked about openly from a cultural standpoint [7].

Wallin et al conducted cross-cultural interviews on 19 Somali adults with type 2 diabetes living in Sweden to describe the daily life experiences of these patients, different gender perspectives, and the effect of diabetes on religious practices such fasting during the month of Ramadan [22]. For most of our Somali pediatric patients, Ramadan did not appear to be a major concern, since children are not expected to fast, and abstinence from fasting is permitted in individuals with a medical condition such as diabetes, where it could potentially place them at risk.

The finding of worse glycemic control in Somali pediatric patients compared to non-Somali patients is consistent with data from Finland, where mean HbA1c among 15 Somali children with diabetes was 9.3±2.2% compared to 8.3±1.5% in non-Somali children ($p<0.001$) [15]. Similarly, studies of adult Somali patients with type 2 diabetes have shown worse glycemic control

compared to non-Somalis [20]. In our cohort, the poorer glycemic control was largely confined to adolescent patients. While adolescents, in general, tend to experience worse glycemic control than younger children [44], immigrant youth may face additional challenges as they struggle with the normal adolescent task of fitting in with their peers. Socioeconomic factors may also play a role in poor diabetes control in Somali adolescents. Children from ethnic minorities are known to have worse diabetes control than non-minority children [15, 18, 19]. More than half of our study participants did not provide specific socioeconomic data, so it was not possible to assess its effect in the current study. However, the majority of these subjects receive medical assistance. Other issues that are immigrant-specific that need to be explored are the literacy levels of the parents, the general stresses of cultural assimilation, and cultural issues surrounding diet. Anecdotal clinical experience suggests that Somali parents, who may have experienced food insecurity during their lives, are reluctant to limit food or beverage intake in their children. More study is necessary to further determine the root causes for these differences in overall diabetes control.

One area the survey identified that warrants further attention is the difficulty that patients and parents experience in calculating carbohydrate content of traditional Somali food for the purpose of insulin adjustment. The typical Somali diet is rich in carbohydrate and contains foods not often identified in Western carbohydrate counting books and charts. This problem is compounded by the fact that the medical team may not be familiar with these foods and thus is unable to provide appropriate advice. We are currently engaged in an effort to develop these materials.

The primary limitation of this study is the small sample size. We will continue to follow these patients and new Somali patients entering our practice over time to gain a greater understanding of the challenges and successes they experience. The survey did not focus on difference in gender perspectives in relation to diabetes, but this is an important area for future research. Further, the survey used in this study was not validated; it was, however, developed to encompass the main concerns that had surfaced during clinical visits with patients and their families. The open-ended questions allowed for the opportunity to learn and embrace new ideas, concerns or misconceptions this survey did not address.

In conclusion, while Somali parents and children cope well emotionally with the diagnosis of T1D and enjoy a trusting relationship with their health care team, diabetes control is poor in Somali adolescents. Lack of traditional dietary resources has emerged as one specific problem that can be better addressed.

Chapter Four: Conclusion

Thesis conclusions

The first paper demonstrates that diabetes is at least as common in Somali children as in the general US population, and it is clearly autoimmune in origin. In contrast to African Americans, DR3 genotype appears to be particularly preponderant, and DR4 is of minimal importance in Somalis with T1D.

The second paper demonstrates that while Somali parents and children cope well emotionally with the diagnosis of T1D and enjoy a trusting relationship with their health care team, diabetes control is poor in Somali adolescents. Lack of traditional dietary resources has emerged as one specific problem that can be better addressed.

Limitations

The biggest limitation of this study is the small subject number, which can lead to erroneous conclusions in genetic analyses. Despite this, the findings largely agree with the findings of a small Finnish study. Enrollment is ongoing in an attempt to capture as many participants as possible so that the sample will be representative.

An additional limitation is the lack of genetic background information on the general Somali population. Efforts are in place to obtain HLA type information on non-diabetic Somalis in Minnesota.

Future directions

Describing HLA types in Somalis without diabetes

Results from this work, showed that Somali children with T1D have an exceptionally higher frequency of DR3 alleles, a finding that is different from African Americans and Caucasians. I am currently obtaining DNA samples from members of the Somali Community who do not have diabetes, to determine whether DR3 differences are related to diabetes per se or

if they are merely a reflection of the genetic background of the Minnesota Somali population in general.

Exploring potential contributors to poor glycemic control

Through working with Somali children and adolescents with diabetes, it became evident that Somali adolescents have worse diabetes control than the rest of the T1D clinic population at UMN.

Little is known about how differences in Somali families and communities might be influencing this discrepancy in diabetes control, therefore, I plan to understand and describe psychosocial, socioeconomic, cultural, familial or educational factors that might be preventing Somali adolescent patients with T1D from having optimal glycemic control.

Establishing educational material

The work described in this dissertation included developing a survey examining the cultural and religious beliefs related to diabetes in the Somali population. The goal was to use information from survey responses to identify common misconceptions, to develop educational tools that specifically target Somali patients and their families, and to provide resources that are culturally relevant and address concerns unique to this population. Interestingly, lack of resources for counting carbohydrates in traditional Somali foods emerged as an obstacle precluding adequate and accurate insulin dosing in these patients and ultimately affecting glycemic control. This has triggered an effort to develop specific Somali dietary resources. I am currently working on a University of Minnesota CTSI, Children's Hospitals and Clinics of Minnesota, & UMN Pediatric Department grant proposal to improve diabetes management in Somali children and adolescents in Minnesota, in response to an RFA designed to support collaborative research addressing important and unmet human child health issues in Minnesota. The project will involve development of video and picture-based educational materials (since many parents are illiterate), written materials in the Somali language, continuing work on a carbohydrate counting booklet which is specific for traditional Somali foods, and creation of support groups for parents of young Somali children with T1D. The ultimate goal is to improve delivery of effective diabetes education to this population in order to improve diabetes control.

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