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Syrian Refugee Health: A Qualitative Analysis Of Experiences With The U.s. Healthcare System

Eunice M. M. Defilippo

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Syrian Refugee Health:
A Qualitative Analysis of Experiences
with the U.S. Healthcare System

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

By
Eunice Modupe Martins DeFilippo
2018
ABSTRACT

SYRIAN REFUGEE HEALTH: A QUALITATIVE ANALYSIS OF EXPERIENCES WITH HEALTHCARE IN THE UNITED STATES. Eunice M. M. DeFilippo, Amer Abdullah, Tracy L. Rabin. Department of Internal Medicine, Yale University School of Medicine, New Haven, CT.

As refugee populations worldwide increase exponentially, there is growing concern for the health needs of these displaced individuals. This qualitative study examines the illness experiences of newly arrived Syrian refugees as they navigate the complex U.S. healthcare system, in an attempt to identify and characterize potential barriers to care that can be addressed. The specific aims of this study are to understand the experiences, beliefs, and practices regarding general health and healthcare delivery amongst newly arrived Syrian refugees obtaining care at Yale New Haven Hospital. Twenty individuals were recruited to participate in semi-structured interviews. An Arabic language interpreter was present. Interviews were audio-taped, transcribed, and coded by a multidisciplinary team using grounded theory and analyzed for emergent themes. Participant ages ranged from 20-64; nine were female. Preliminary analysis of five transcripts revealed the following major theme: Unmet expectations for healthcare delivery and patient-provider interactions leads to experiences of perceived healthcare system inaccessibility and insufficiency. Participants described frustration with: 1) Lengthy Wait Times for Care, 2) Prescription Requirements, 3) Delayed Access to Specialists, 4) Dismissed Chronic Complaints, and 5) Language Barriers. Unexpected shifts in care delivery also contributed, such as a lack of knowledge to understand the 1) Referral System, 2) Prescription Drug System, or their 3) Insurance Limitations. As a result, participants experienced delays in care leading to 1) Frustration, 2) Mistrust, and the 3) Reliance on Traditional Medicines. This preliminary analysis reveals key challenges to accessing the U.S. healthcare system and limitations in refugee-provider interactions that may contribute to patients disengaging from care, and are critical to address in efforts to improve care for this population.
ACKNOWLEDGEMENTS

I would like to thank the refugee families who graciously agreed to share their stories. They taught me profound lessons immersed in faith, family, food, and the physician role as provider and advocate. My hope is to pass these lessons on to those who care for the most vulnerable.

I would like to thank my faculty advisor, Tracy Rabin, who gave me the tools, inspiration, guidance, and confidence to build this research project from scratch. From the research question, to the methodology and analysis, she challenged me to define, understand, and execute each step of the process and in doing so sincerely trained me in the art and science of research.

Thank you to Amer Abdulla, an inspiring, generous, and genuine surgeon from Syria who worked side-by-side with me at almost every step of the project. His contribution and partnership has been invaluable.

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Chapter 1: BACKGROUND

1.1 – Introduction

The United States has one of the largest refugee resettlement programs in the world, resettling over 3 million refugees since 1975.\(^1\) Though current refugee health guidelines from the Center for Disease Control and Prevention focus on communicable disease surveillance and immunization requirements, a growing body of literature reveals concerning non-communicable disease (NCD) trends amongst resettled refugees that remain overlooked and under-addressed.\(^2-5\) Rates of NCD’s in this population are similar to those of the general U.S. population, but additional data suggest that complications from these diseases are more aggressive and insidious.\(^4, 6\) In addition, refugees often arrive from regions with surging rates of NCD’s, particularly diabetes, hypertension, hyperlipidemia, overweight, and obesity.\(^7, 8\) Once resettled in the U.S., they may face many of the same health risks and access barriers faced by their non-refugee immigrant counterparts.\(^7-9\)

After experiencing an abrupt loss of healthcare and general health needs with the onset of persecution (due to race, religion, war, etc.), refugees worldwide often struggle to find consistent, affordable, and adequate healthcare during their many years awaiting resettlement.\(^8\) This growing problem coincides with what UNHCR’s Filippo Grandi calls “the greatest humanitarian crisis of our era,” — the Syrian refugee crisis. The urgent and ongoing calamity has led to the resettlement of Syrian refugees who have experienced multiple health struggles as a result of rapid displacement. This unique predisposition warrants further examination, evaluation, and monitoring regarding the
health of the many global communities of refugees, Syria and others, as they transition to the vast and perplexing U.S. healthcare system.

In this state of high risk for non-communicable disease onset, morbidity, and mortality, resettled refugees appear to experience patterns of weight gain and NCD development overtime, yet the mechanisms for these changes are not completely clear. Some suggest that post-resettlement NCD patterns are linked to acculturation-related lifestyle changes after arrival, however, inconsistencies remain in the definitions and measurements of acculturation, limiting its reliability.\(^{(10, 11)}\) In addition, as refugees acclimate to U.S. culture, it is unclear how they fall through the cracks of our healthcare system. What are the events, beliefs, and practices that lead them there? What role do providers have in creating or reinforcing barriers to care? As increasing political, religious, climate-related, and economic instability in low- and middle-income nations continues to displace refugees, this influx of individuals with chronic health needs poses an important post-resettlement public health challenge. Unfortunately, an existing gap in the literature remains regarding the particular health needs of this population and additional research is necessary to prepare communities and providers to care for their newest patients.

\[\textbf{1.2 - The Global Non-Communicable Disease (NCD) Epidemic:}\]

In centuries past, the global burden of disease has landed heavily in the realm of infectious, communicable diseases. However, with globalization, urbanization, and increasing lifespans worldwide, chronic diseases such as diabetes, hypertension, cardiovascular disease, hyperlipidemia, overweight, and obesity have become of
increasing concern. Recent studies on the global burden of disease have demonstrated a shift away from communicable diseases and into the current NCD epidemic, a crisis that places the heaviest physical and economic burden on low-income nations. According to the World Health Organization Global Status Report on Non-communicable Diseases 2014, NCD mortality made up 68% of global deaths in 2012, ~75% of those deaths occurred in low- and middle-income nations. In addition, 48% of NCD deaths in low- and middle-income nations were estimated to occur in individuals under 70 years of age, during their peak time of contribution to the economy.\(^1\)\(^2\)\(^4\) By 2030, NCD’s will account for three times as many disability-adjusted life years as communicable diseases in low- and middle-income nations.\(^5\) This epidemic of illnesses is far-reaching, off-setting the progress of the Sustainable Development Goals and becoming an economic burden for families worldwide.\(^6\) Unfortunately, approximately 100 million people fall into poverty each year trying to pay for NCD-related health services.\(^5\)

### 1.3 - The Epidemiologic Transition:

In resource-limited settings, the transition from communicable diseases to NCD’s has been ongoing for decades. In 1971, Omran Abdel was the first to coin the term “epidemiologic transition,” a theory of population dynamics that describes the shift in mortality and disease prevalences when medical advancements reach developing nations. This theory defined the natural decline in infectious disease epidemics, the subsequent population growth, and the ultimate rise in chronic non-infectious disease morbidity and mortality in these nations. He and others posited that this phenomenon occurred as a result of the health and socioeconomic impacts of economic improvement, urbanization,
an aging population, and the adoption of a diet high in animal fat and refined sugar.\textsuperscript{(17, 18)}

The epidemiologic transition was particularly a concern for the Middle East, where the exporting of oil vastly improved the gross domestic product of most nations. As money poured into their economies, healthcare advanced, and mortality from communicable diseases declined, paving the way for this region to possess one of the fastest population growth rates in the world.\textsuperscript{(19)} By the 1990’s, agricultural data from the Middle East showed a doubling of per capita food energy and protein availability, a tripling of fats availability, a five-fold increase in rice availability, and a general decrease in vegetable availability.\textsuperscript{(17, 18, 20)} These changes, along with rapid urbanization, were crucial in shaping the ensuing upsurge in rates of overweight- and obesity-related disease in the Middle East. As he predicted, NCD’s are now among the most prevalent conditions in the region.

\textbf{1.4 - Diabetes and the Middle East:}

One of the chronic diseases most concerning in the Middle East is type 2 diabetes, the prevalence of which has risen substantially over the past several decades. As expected, the explosion of diabetes in the Middle East predictably followed the arc of fast-growing economies and rapid westernization, leading to uncontrolled weight gain and obesity, a key physiologic factor in diabetes pathogenesis for many.\textsuperscript{(21)} This has placed an immeasurable strain on economies in the region, as diabetes is a costly disease to treat and the complications are costly as well.\textsuperscript{(12, 22)}
In the decades since Abdel’s theory was described, the Middle East experienced a rampant outbreak of obesity and type 2 diabetes, the peak of which has likely not yet been realized. Unfortunately, this severe morbidity, premature mortality, and disability has risen disproportionately in the region. King, et. al. highlighted that the alarming surges in prevalence rates for diabetes and impaired glucose tolerance (IGT) in low- and middle- income nations were similar to those amongst marginalized populations within higher-income nations.\(^{(23)}\) In 1989, the World Health Assembly responded to the growing global concern with their release of guidelines for the implementation of national diabetes programs. Middle Eastern nations began to implement these programs in order to accurately quantify and address the diabetes problem in their region.\(^{(23, 24)}\) Despite these efforts, the rates of diabetes in the region have continued to rise.

As immigration from the Middle East to the U.S. increased substantially in the 1990’s, diabetes in these communities mirrored that of the Middle East region.\(^{(25)}\) In 2003, Jaber, et. al. studied the prevalence of diabetes, impaired glucose tolerance (IGT), and impaired fasting glucose (IFG) amongst Arab Americans in Michigan. The rates she found closely resembled those endorsed by researchers in other regions, increasing the concern as high rates of IGT in a population can be a harbinger for a looming diabetes endemic.\(^{(23)}\) She found combined prevalence rates amongst men and women of 49.8% and 32.3%, respectively, and as predicted, these rates were closely associated with obesity-related risk factors such as higher BMI and waist-to-hip ratios compared to controls. Her study and many others support the idea that the global rise in overweight
and obesity, particularly in the Middle East and amongst U.S. immigrants from the region, has become the fertile soil in which the current diabetes epidemic has thrived.(26)

Over the last two decades, these trends in the Middle East have persisted. According to data from the International Diabetes Federation in 2011, four middle eastern nations ranked highest worldwide, close to 20%, for the prevalence of diabetes (Saudi Arabia, Kuwait, Qatar, and Lebanon).(27) Amongst the eighty most populous countries, Syria ranked 9th with a prevalence of ~10%, though some argue that due to limitations in data collection these data are likely grossly underestimated.(27-29) Now, in the era of the Syrian conflict, the largest refugee crisis since World War II, some suggest that diabetes is the most common chronic disease in Syria. This trend warrants particular focus on risk factors and management of this disease in this particular population.(29)

As refugees from the Middle East resettle in the U.S., diabetes is of particular concern due to the complex management steeped in challenging changes in lifestyle, the necessity for health literacy, and its life-threatening complications.(30) The 2013 Global Burden of Disease study showed a 132.9 percent change in prevalence of diabetes from 1990-2013, and showed its climb from number 10 to number 7 globally in the top 25 causes of DALY’s, years lived with disability.(31) The work of being a patient with diabetes might involve monitoring blood sugars, planning meals and physical activity, coordinating diabetes treatments with the treatments of other conditions, implementing treatment programs into existing daily routines, injecting insulin and/or taking oral medications, and being attentive to symptoms of hypoglycemia. The ability to carry out these
treatment plans depends upon many personal factors (self-efficacy, resilience, literacy), health (physical and mental function), material resources and support, and social support, among other factors. This difficulty with diabetes management is evidenced by national data from NHANES showing that despite many improvements over the last 10 years, 30-50% of U.S. diabetic patients did not meet individualized targets for glycemic control or risk factor modification (blood pressure, smoking, lipid control). Refugees from the Middle East region are arriving already at higher risk for this disease, many even with undiagnosed IGT and diabetes; their capacity to carry out these complex treatment plans and lifestyle changes are compounded by the unique linguistic, economic, and cultural struggles they face while acclimating to life in the U.S.(32, 33)

1.5 – U.S. Immigrant and Refugee Health:

Historically, the U.S. has struggled with the health of its immigrants, particularly with access to care issues, chronic disease prevention, and strategies to effectively combat the post-migration rise in overweight and obesity.(34, 35) In 2000, Anahid Kulwicki and Stephanie Schim conducted a qualitative study amongst Arab Americans, nurse researchers, and healthcare system administrators regarding the quality of care received and whether it was culturally competent. This study outlined many themes that are still a concern today for newly arrived immigrants from the Middle East, including the language barrier, lack of awareness of Arab cultural and religious values, lack of knowledge about the United States health care system, and difficulties with accessing the health system. Not only did Arab Americans endorse issues with wait times for appointments, but providers noted a resistance to “cater” to this population and treat them
“better” or “special” compared to others.\textsuperscript{(36)} These findings suggest experiences and barriers that are likely similar to those faced by resettled refugees arriving from the Middle East region.

In terms of refugee health, the U.S. provides newly arrived refugees with health insurance for eight months after arrival. However, studies conducted by Yun, et al. in 2012 highlighted troubling NCD health statistics seen at the Yale New Haven Hospital Adult Refugee Clinic, a partner with the local refugee resettlement agency, Integrated Refugee and Immigrant Services. Over half of the adults studied were overweight and obese with high rates of dyslipidemia, all associated with type 2 diabetes. Of particular concern was the finding that the prevalence of NCD’s was similar to that of the general U.S. population overall (adults aged 18-64 years), but among a younger cohort of refugees, as 85\% of the study population was 45 years or younger. In addition, her 2012 study of refugee insurance status after receiving legal permanent residency using a national dataset showed that almost 50\% of refugees with chronic conditions were uninsured.\textsuperscript{(37)} In light of these findings, she advocated for systems to address the long-term health needs of this population who suffered from a high burden of non-infectious morbidity.

Since 2008, close to 50\% of refugee admissions to the U.S. have arrived from the Near East and South Asia region.\textsuperscript{(38)} In Connecticut, the New Haven refugee population includes refugees from the Middle East, Northern Africa, and a variety of other regions, though since 2010 over 60\% of all resettled refugees arrived from the Middle East (Afghanistan, Iran, Iraq, and Syria). This high percentage of refugee resettlement from
the Middle East has increased with the influx of Syrian refugees due to the current conflict and resultant global refugee crisis. While this is a unique population that has been displaced over a short amount of time, the present literature studying the health of these vulnerable people as they engage with healthcare systems is still in its infancy. In addition, refugee resettlement globally and nationally prioritizes individuals with disabilities, serious medical conditions, and in need of urgent medical treatment. Those resettled from the Middle East region arrive from areas with worrisome rates of chronic disease morbidity and often lacked adequate healthcare during their years awaiting resettlement.\(^{(7, 8, 17, 28, 39, 40)}\) Using diabetes as an example, this project aims to help close the current gap in knowledge regarding the experiences and challenges these individuals face as they navigate the U.S. healthcare system. The goal is to use the following data to inform targeted interventions and to provide insights for the providers caring for these individuals.
Chapter 2: STATEMENT OF PURPOSE

The purpose of this study is to understand the experiences, beliefs, and practices regarding general health, healthcare delivery, and type 2 diabetes amongst newly arrived Syrian refugees at Yale New Haven Hospital.

Aims:

1. To characterize and understand experiences related to general health, healthcare delivery, and type 2 diabetes, including prevention and management.

2. To understand specific beliefs and practices that could inform targeted interventions related to general health, healthcare delivery, and type 2 diabetes in this population.
Chapter 3: RESEARCH METHODOLOGY

3.1 – Research Design

We used an inductive, qualitative research study design. Qualitative methods were chosen because of the exploratory nature of this study for which prior literature is limited.\(^\text{41}\) In addition, the unique vulnerabilities, traumatic experiences, and challenges faced by the Syrian refugee population warranted a primary theoretical analysis to generate applicable frameworks, theories, and hypotheses. We considered it more valuable to begin our evaluation of New Haven Syrian refugees within this context, rather than examining this population based on predetermined notions.

Qualitative research is concerned with understanding the meanings and associations individuals assign to their experiences with a particular phenomenon, system, or situation.\(^\text{42}\) The ambition of qualitative research is to engage and evaluate the scientific data that cannot be described, controlled, or measured statistically, using this voice to frame discussions around the significance and consequence of quantitative outcomes. In one type of qualitative methodology often used in the health sciences – grounded theory – researchers conduct iterative analyses through which textual data is scrutinized to develop thematic frameworks that highlight the essence of collective individual experiences. From these themes, the developing frameworks, theories, and hypotheses can be further analyzed in the study population. According to Kitto et. al., qualitative and quantitative research differ in their measurement of “trustworthiness.” While generalizability, reliability, and validity are expected scruples of quantitative research,
qualitative methodology hinges on “rigour…, credibility…, and relevance…” (43). Qualitative research strives for “conceptual generalizability” wherein the concepts generated apply to relevant healthcare settings that differ from those used in the study. (43, 44)

Qualitative methodology does not engage hypotheses in the traditional sense, but rather aims to generate them or challenge them by exposing nuanced perspectives (45). Therefore, following a thorough search of the literature, we undertook this qualitative study speculating that amongst newly arrived Syrian refugees, there were relevant shared experiences related to general health, healthcare delivery, and type 2 diabetes, that could inform care delivery and intervention for this population.

Much evidence exists for the direct benefit of qualitative literature to improving the efficacy, applicability, and relevance of healthcare delivery in multiple contexts (44). In addition, due to the qualitative ideology of engaging with experiences and opinions in their real-world settings, qualitative research is uniquely suited to provide insight and direction for providers of unique patient populations.

3.2 - Participants

The study protocol was approved by the Yale University Institutional Review Board in March of 2017.
We recruited newly arrived Syrian adult refugees resettled by the local resettlement agency IRIS (Integrated Refugee and Immigrant Services) and seen for their domestic medical evaluation at the Yale Adult Primary Care Center refugee clinic.

**Purposive Sampling:**

As qualitative research is iterative and is based on developing hypotheses, theories, and themes rather than making generalizations about populations, purposive sampling was employed. Purposive sampling involves choosing participants based on characteristics or sampling frames that are related to the research question to obtain the richest data possible. (42, 46) To this end, it is not necessary for the population to be randomly sampled or representative in qualitative research, but rather that the participants are varied and diverse enough to increase the richness of the data. While quantitative samples must be representative for generalizability, Kitto et. al. argues that qualitative methods seek *conceptual generalizability or transferability*, which is concerned with the ability of the results to provide guidance in settings that vary from those used in the study. (43)

Sampling is also iterative; it is influenced by incoming data in real-time and it evolves along with the purposive methods, as described above. Thus, sampling is discontinued and data collection is complete once thematic saturation is reached, that is there are no new themes or concepts emerging from the data. (42, 46, 47) Therefore, there is typically no pre-determined sample size due to the nature of this process. However, a typical sample size goal set in qualitative research is 20 interviews, which is the goal we have chosen, though saturation may be reached earlier or later.
**Sampling Frames:**

Sampling frames allow the qualitative researchers to create a pool of participants to recruit from whereby individuals contain specific attributes or fall into specific categories that are pertinent to the research question. From this pool, purposive sampling may be employed.\(^{46}\) Recent literature suggests that living in urban settings carries an increased risk for non-communicable diseases, especially for individuals living in low- and middle-income nations.\(^{48}\) For this reason, as well as for heterogeneity of our sample, we recruited individuals originating from urban areas in Syria. In addition, we were interested in those who had recently arrived in the U.S. for the purpose of capturing sentiments regarding general health, healthcare delivery, and type 2 diabetes most representative of life in Syria and its contrast with the U.S. healthcare system. We also intended to inquire about their understanding and experiences with diabetes prior to arrival. Our sampling frames included:

1.1. Syrian adult refugees (>18 y/o)

1.2. Arrival within 6 months prior to creation of the recruitment list (on March 9, 2017)

1.3. Men and Women

1.4. Originating from urban areas

1.5. Varying ages: 20s-40s; 50s-60s

**Criteria:**

The following inclusion and exclusion criteria were used.

1. Inclusion Criteria:
a. Adults (>18)
b. Syrian, originating from urban areas
c. Refugee Status
d. Currently living in CT
e. Received care at the Yale Adult Refugee Clinic

2. Exclusion Criteria:

   a. Living in the U.S. for > 6 months from recruitment list creation
   b. Unable to consent (decisionally impaired)
   c. Refused audiotaping of the interview

3.3 - Recruitment:

With the support of the Joint Data and Analytics Team at Yale New Haven Health, we created a report in the EPIC electronic medical record (EMR). This report generates a list of all individuals that have been seen at the Yale Adult Refugee Clinic since September 9th, 2016, six months prior to the start of recruitment. This report included 30 individuals with the following variables: name, sex, age, telephone number, last encounter date. Through this list individuals were recruited in Arabic via telephone using a recruitment script (Appendix A). During recruitment phone calls, the country and city of origin of participants were confirmed. The script explained the purpose of the study and brief information about the participants role. Our research team member Amer Abdullah (AA) is a well-known member and advocate of the Syrian community in New Haven, speaking at informal and religious meetings to help orient refugees to life in the United States. His familiarity and pre-existing relationship with these individuals made him the most experienced member of
the research team to recruit these individuals via telephone and invite them to the interview events. During recruitment calls, it became clear that many participants on the recruitment list were related, most of whom were husband and wife couples, though some were adult children and their parents. Verbal consent was recorded and participants received a translated copy of the consent form at the time of the interview. Participants were remunerated with 20$ giftcards to a local supermarket. After 20 participants were interviewed, recruitment was concluded.

3.4 - Data Collection:

Setting: Participants were interviewed individually in a classroom at the Yale School of Medicine Anlyan Center for Medical Research and Education. Family members were either seated in the hallway or in an adjacent room.

Interviews: Semi-structured interviews were conducted using an interview guide. Appendix B contains the interview guide questions and probes. All interviews were conducted in Arabic by Eunice Martins (EM), principal investigator, and Amer Abdullah (AA), Arabic interpreter, co-investigator, and former general surgeon from Syria. Verbal consent was recorded prior to the start of each interview.

Both interviewers received interview guidance from qualitative researchers and experts, and conducted three practice interviews using volunteers known to AA or EM. Preparation also included select videos on data collection and analysis from Dr. Leslie Curry’s YouTube series, *Fundamentals of Qualitative Research Methods.*
3.5 - Interview Guide:

The interview guide (see Appendix B) was developed through literature review as well as by obtaining feedback from key informants, including diabetes experts, refugee health experts, qualitative research experts, and a community liaison. There is a certain flexibility built into the interview guide, as is established in qualitative research, where the interview guide is influenced and modified by emerging theory throughout data collection. This allows the study to follow and be influenced by the conceptual ideas that are uncovered during the ongoing analysis and reinforces the richness of the data.

3.6 - Demographic and Health-Related Characteristics:

We asked each participant to respond to demographic questions prior to the start of the interview on the following parameters. The answers were recorded into an online Qualtrics survey. The participants did not need to complete any forms or surveys online. These descriptive demographic characteristics helped us to assess the diversity of our sample:

1. Home country and city
2. Preferred language
3. Age
4. Gender
5. Refugee camp exposure and length of time spent there
6. Living in an urban or rural setting prior to the Syrian conflict
7. Education level prior to arrival
8. Whether the participant has diabetes
9. Whether the participant has a friend/family member with diabetes
10. Pre-arrival weight and height (subjective)
11. Whether the participant has ever smoked cigarettes
12. Whether the participant consumes alcohol

In addition, we collected the following health characteristics from the electronic medical record of all participants.

- Whether the participant has a diagnosis of diabetes in their electronic medical record
- First hemoglobin A1c
- First serum glucose
- First BMI, Last BMI
- First weight/height data from the electronic medical record
- Total Cholesterol (first value)
- LDL cholesterol (first value)
- Systolic blood pressure

### 3.7 - Data Processing:

Interviews and consents were audio-taped on a digital recorder. Digital recordings and Qualtrics surveys were given a numerical code and stored on EM’s password-protected computer as well as on a secure server. A key containing participant names, MRNs, and telephone numbers linked to their codes was stored in a locked cabinet in the office of the faculty advisor, Tracy Rabin’s (TR) office.
The first three digital recordings were transcribed by EM into Microsoft Word and stored on her password-protected computer as well as on a secure server. Any identifying information was edited out of the transcript. The remaining transcripts were sent to Asp.MD, for their transcription services. EM audited all transcripts from Asp.MD for accuracy and identifying information.

3.8 - Data Analysis:

We employed the grounded theory of qualitative analysis. Grounded theory involves inductive data analysis where constant comparisons of the textual data are employed and from which major themes and concepts emerge. This process involved line-by-line de-novo coding of each transcript. Coding is a process where textual data is organized into small chunks of similar data, each with a particular label. Transcripts were coded by EM, AA, and TR. EM and AA coded transcripts 1-3 individually and then met with each other and with TR to negotiate and reach consensus on the assigned codes. This process was used to ensure inter-rater reliability. After the first three transcripts were coded and negotiated, EM coded transcripts 4 and 5 and has contributed these to the current analysis.

Codes were further refined into major categories until the final codebook was developed. A list of final negotiated codes can be found in Appendix C. Subsequently, all five transcripts were uploaded into the ATLAS.ti qualitative data analysis software (version 8.1.3). Within this program all transcripts were re-coded using the final codebook. Through rigorous literature review of the emerging themes and concepts, along with comparative analysis of similarly coded portions of data, major themes and frameworks were described.
Chapter 4: RESULTS

4.1 - Demographic Characteristics:

A total of 20 interviews were conducted with adult Syrian refugees originating from urban areas in Syria, all of whom had lived in the U.S. for less than one year. There were 9 women and 11 men interviewed; the majority were either husband and wife couples or related to other participants. Participants varied in age, education level, occupation, and city of origin. Their descriptive demographic characteristics are outlined in Table 1.

Participant ages ranged from 20-64; fifteen were <35 years and five were 40 years or older. The majority of participants (12) originated from Homs, a city lying along the northern border crossing between Syria and Lebanon. Other cities of origin included Damascus, Dar’aa, and Hamah. While Hamah lies north of Homs, Damascus also resides near a border crossing between Syria and Lebanon. Dar’aa lies near the border between Syria and Jordan. Most Syrian refugees originate from these cities as they were closest to the countries of refuge. In addition, these are the primary countries of transition where Syrians await resettlement. For a map of Syria, see Appendix D.

In terms of education, two participants did not complete any elementary school. Eleven participants completed some form of schooling, but did not complete high school, and the remaining five participants completed at least some vocational school, technical school, or college. When prior occupation was able to be confirmed via review of the electronic medical record, the occupations of the male participants varied widely, including
business ownership, laboratory technologist, electrician, and construction worker. In addition, two women reported their occupation as homemaker.

While almost half of the participants reported going to a refugee camp after fleeing Syria, only 4 participants, a family of four (mother and three adult children), stayed in the refugee camps for more than one month. As mentioned by two couples, the condition of the camps was deemed so severe that they absconded to live undocumented in the nations to which they fled. This is consistent with trends showing a growing number of refugees residing in urban areas, rather than camps, and raises concern for poor health status as non-camp refugees tend to have poor access to health services and higher rates of chronic diseases.\(6, 8\)

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<td>City of Origin</td>
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<tr>
<td>Refugee Camp Exposure</td>
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<tr>
<td>Level of Education</td>
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</table>
4.2 - Additional Health-Related Characteristics:

Table 2 shows responses to smoking history and alcohol use where 12 participants reported having ever smoked but only one participant admitted to alcohol use. This may be related to the explicit prohibition of alcohol use in the Qu’ran, compared to less explicit language regarding smoking.(49) Table 3 shows laboratory data obtained from the EMR of the Yale Adult Refugee Clinic Intake visit or domestic medical examination, including BMI and diabetes-related data. Five participants had diabetes, three of whom had a hemoglobin A1c of 9 or greater, suggesting poor glycemic control; two participants had hemoglobin A1c values in the prediabetes range. Of note, half of the participants did not have their hemoglobin A1c evaluated during the study period. The remaining participants either knew of a relative or friend with diabetes and contributed salient diabetes-related stories and experiences.

<table>
<thead>
<tr>
<th>Table 2: General Health Demographic Characteristics</th>
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</thead>
<tbody>
<tr>
<td>Smoking History</td>
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<tr>
<td>Smoking History</td>
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<tr>
<td>Smoking History</td>
</tr>
<tr>
<td>Alcohol Use</td>
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<tr>
<td>Alcohol Use</td>
</tr>
</tbody>
</table>
Table 3: General Health Characteristics (obtained from the EMR)

<table>
<thead>
<tr>
<th>First Recorded Body Mass Index (BMI)</th>
<th>18-25</th>
<th>25-30</th>
<th>&gt; 30</th>
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<tbody>
<tr>
<td>Diabetes Diagnosis</td>
<td>Yes</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>HgbA1c</td>
<td>Not Evaluated</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>&lt;5.7</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5.7-6.4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt;6.5</td>
<td>5</td>
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</tr>
<tr>
<td></td>
<td>&gt;/= 9</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>SBP</td>
<td>&lt;120</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>120-139</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>140-159</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt;/= 160</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Cholesterol</td>
<td>LDL Cholesterol &gt;160</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>LDL Cholesterol Not Evaluated</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total Cholesterol &gt; 200</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total Cholesterol Not Evaluated</td>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>

Figure 1 in Appendix E shows participant BMI data. On average, domestic medical examinations for newly arrived refugees in the U.S. should take place within the first month after arrival, however some occur earlier or later amongst the participants in our sample, during which significant weight gain or loss could have occurred. However, at the time of the domestic medical evaluation, twelve participants had a BMI >25, of which six had a BMI over 30 (meeting criteria for a diagnosis of obesity). In addition, each participant was asked about their pre-arrival weight so that a subjective “pre-arrival” BMI could be calculated using height data from the electronic medical record. Figure 1 shows that while only 3 participants overestimated their BMIs compared to actual BMIs on arrival, 14 participants underestimated their pre-arrival BMIs. Seven of those 14 participants underestimated their actual BMIs by over 1.0 BMI unit. Two subjective
BMIs were unable to be calculated as participants could not recall a “pre-arrival” weight. These findings are in agreement with previously documented trends of post-arrival weight gain amongst resettled refugees.\(^4, 50\)

BMIs from the initial domestic medical evaluation were compared to the most recent recorded BMIs in the electronic medical record at the time of study recruitment. The time interval between these BMI measurements ranged from 3 months to over 1 year; the majority of participants at least a six month interval between the initial and most recent BMI measurements. One participant did not have a follow-up reading after the initial domestic medical evaluation.

### 4.3 – Emerging Themes and Theoretical Frameworks:

The main domains of our interview questions included topics regarding general health and diet, diabetes-related knowledge and experiences, and experiences with healthcare providers and the healthcare system in the United States. Outlined in Figure 2 are the four major themes emerging from analysis of the first five transcripts, along with short phrases used to describe them; we are not yet certain that we have reached thematic saturation. **Theme 1:** Culturally informed beliefs around food shape understanding of the relationships between food and health. **Theme 2:** Unmet expectations for healthcare delivery and patient-provider interactions lead to experiences of perceived healthcare system inaccessibility and insufficiency. **Theme 3:** Cultural beliefs about psychological and emotional stress influence understandings of disease etiology, and prevention and management strategies. **Theme 4:** Individual chronic illness narratives permeate social
networks to shape a specific set of shared knowledge, attitudes, beliefs, and behaviors. Multiple sub-themes also emerged and at times overlapped with each other. These are arranged in Figure 3.

Figure 2:

Core Emerging Themes

| What are the experiences, beliefs, and practices regarding general health, healthcare delivery, and Type 2 Diabetes amongst newly arrived Syrian refugees at YWHA. |
|---|---|
| **RELATIONSHIP BETWEEN FOOD AND HEALTH** | **Theme #1:** Culturally informed beliefs and practices around food shape understanding of the relationships between food and health. |
| **HEALTHCARE SYSTEM DERIVATION** | **Theme #2:** Unmet expectations for healthcare delivery and patient-provider interactions lead to experiences of perceived healthcare system inaccessibility and insufficiency. |
| **ILLNESS PSYCHOLOGY** | **Theme #3:** Cultural beliefs about psychological and emotional stress influence understandings of disease etiology, and prevention and management strategies. |
| **CHRONIC ILLNESS NARRATIVES** | **Theme #4:** Individual chronic illness narratives permeate social networks to shape a specific set of shared knowledge, attitudes, beliefs, and behaviors. |

*Figure 2:* Emerging Themes. The four major themes emerging from the preliminary analysis of five transcripts are outlined.
Figure 3: Emerging Themes. A diagram of the four major emerging themes and their associated sub-themes are shown above. Arrows indicate the conceptual relationships between themes and sub-themes.

In the following sub-sections, Theme 1, Theme 3, and Theme 4 will be briefly discussed. However, an in-depth discussion using multiple supporting quotes will be reserved for the most prominent theme, Theme 2, in Chapter 5. In addition, the discussion section refers specifically to the results of Theme 2.

**Theme 1: Culturally informed beliefs around food shape understanding of the relationships between food and health.** Participants consistently noted the relationship between the health impact of the food they consumed. Comments focused on either food as a toxin or food as a form of medicine. Discussions regarding the toxic nature of food were related to the shifts in food culture experienced during transition and resettlement. Several participants described an aversion to the U.S. food culture, due to beliefs that the methods of U.S. food production and processing, along with the predominant fast food
culture, were toxic to the body. One woman commented on this relationship between food and health:

[3]: “The diet contributes a main and an important role about all this stuff...even here when they are planting some vegetables, they put all these chemical stuff and these chemical stuff goes to our body. It’s all hormones...even the chickens they are inject the chickens with hormones. How will you imagine our bodies will become?”

The processed nature of foods was evident to participants by the “lack of taste” despite eating similar produce to those consumed in Syria. As a result, individuals reported cooking meals in the home and avoiding “ready foods” from outside. We described this familiarity with natural, fresh, unprocessed foods in Syria and the difficulty navigating the U.S. food environment as a form of aversion to the new food terrain.

In terms of the medicinal use of food, participants described the use of herbal medicines and teas to promote health. One commonly used herbal drink was maté, a popular tea imported to Syria from South America. Participants reported the health benefits of maté, including the stabilizing of blood glucose levels. In addition, participants discussed Prophetic Medicine – health recommendations advocated by the Prophet Muhammad in the Qu’ran and other religious texts of the Muslim faith. They recalled many dietary recommendations, including the benefits of fasting during Ramadan and restricting their diet to halal foods. Muslim faith was ubiquitous amongst our participants and discussions regarding Prophetic Medicine were recurring. Additional details can be found in Figure 4 of Appendix F.

Theme 3: Cultural beliefs about psychological and emotional stress influence understandings of disease etiology, and prevention and management strategies. “Illness
Psychology was the term attributed to this theme, describing the relationship between psychological state and disease. All participants described stories detailing the ways intense emotional states (ie. sudden fear, sadness, anxiety, stress, etc.) act as triggers for the onset of diabetes and other illnesses. One participant summarized this belief:

[4]: “Generally speaking, being sad or getting affected emotionally from anything, it will affect the whole of your body, the whole organs in your body...I am not 100%, but 99% I am sure I get diabetes because I get sad…”

He went on to say:

[4] “I hear that in Syria, many people they get sad and they get diabetes. And you can get diabetes in many ways. You can have a lot of increased intake of sugars or eating a lot of sweets. You can have diabetes by sometimes when you are getting scared or frightened, getting shocked sometimes. Or maybe it is like inherited.”

In addition, others reported avoidance of stress, anxiety, and intense emotions as a way to prevent or manage diseases such as diabetes, particularly with regard to blood sugar control. In terms of prevention, a few participants discussed the difficulty avoiding stress and sadness due to family that remains in Syria and in danger. Two men described dealing with this particular type of psychological stress by smoking, despite the negative health effects. Additional details can be found in Figure 5 of Appendix F.

**Theme 4: Individual chronic illness narratives permeate social networks to shape a specific set of shared knowledge, attitudes, beliefs, and behaviors.** As participants discussed in-depth and salient experiences with diabetes (either personal or through connections to family or friends with diabetes), similarities emerged, forming a cohesive narrative with shared features. Participants described several accounts of severe morbidity with diabetes, including blindness, amputation, and extremity numbness. While most participants also mentioned classic symptoms of diabetes such as frequent
thirst and urination, the stories of severe morbidity and mortality left all participants describing diabetes as a “scary,” “bad,” or “feared” disease. When asked, “What does diabetes mean to you?”, one non-diabetic participant highlighted his impression, echoing the experiences of other participants:

[1]: “…Generally, I don’t like the name. In my opinion, according to my information, diabetes is one of the bad diseases. I count it as bad as cancer and hopefully God keep it away from all of us…”

He went on to describe how he formed this impression:

[1]: “…my dad’s brothers wife, actually, she died because of diabetes and she was suffering a lot and I remember all that stuff. And now I’m seeing my mom and my dad are suffering and struggling with the same problem… One of the difficulties or the stuff that they were suffering from, they were preventing to eat a lot of stuff. They were preventing to do a lot of stuff, and they are preventing to move a lot, and they’re life completely changed. And they’re being so much obsessed like they have to check every single thing and they have to check the blood sugar every single couple of hours to make sure everything is fine and they are struggling with a lot of stuff…”

In 1988, Arthur Kleinman was the first to describe these “illness narratives,” highlighting the importance of the social and cultural contexts through which patients experience illness, and the meanings they assign to those experiences.(51, 52) He suggested that these individual experiences can penetrate social networks and communities, as with our participants, to create collective experiences which then influence knowledge, attitudes, beliefs, and behaviors within that social network.

For example, in terms of health literacy, there were discrepancies in knowledge of diabetes causes and management, though almost all participants reported managing diabetes predominantly through diet and exercise. In addition, participants often reported the use of herbal medicines and Prophetic Medicine for blood sugar management, as discussed above. These social and cultural illness narratives are relevant for providers as
they address chronic disease prevention and management in these communities.

Additional details can be found in *Figure 6 of Appendix F.*
Chapter 5: HEALTHCARE SYSTEM DEPRIVATION

Theme 2: Unmet expectations for healthcare delivery and patient-provider interactions lead to experiences of perceived healthcare system inaccessibility and insufficiency. The most salient themes that arose during discussions with participants centered around experiences with healthcare delivery and the difficulties of acclimating to the healthcare systems, particularly the U.S. healthcare system. While discussing experiences with providers in the U.S., participants often drew comparisons to experiences with the Syrian healthcare system and health systems in countries of transition arrival. As participants compared models of delivery and methods of accessibility between countries, core sub-themes emerged regarding the shared healthcare values these participants left Syria with, and the ways in which these values were unmet in other nations. As outlined in Figure 7, unmet healthcare values were often due to unexpected shifts in healthcare delivery leading to perceived barriers and frustrations that we have termed healthcare system deprivation. In the following sections we will discuss these experiences in greater detail using representative quotes.
5.2 – Unmet Healthcare Values:

Participants described a collective preference for the characteristics of the Syrian healthcare system, and, overall, experienced great difficulty adapting to healthcare systems elsewhere. The unmet healthcare values embedded in these experiences were:

(1) **Timeliness of Care**, (2) **Ease of Accessibility**, (3) **Clear Communication with Providers**, and (4) **Quality of Care**. Two additional sub-themes, though not as prominent as those above, were (5) **Autonomy in Health Management** and (6) **Affordability and Coverage**.

*Ease of Accessibility and Timeliness of Care:*
As participants described their struggle with accessing the U.S. healthcare system, they placed great value on the ease and simplicity of accessibility in Syria. When comparing experiences in the U.S. to those in Syria, participants stated:

[1]: “...in Syria if you are sick, if you are need like emergency situation, you can just go to the doctor immediately. You can call the doctor, listen, if you have a tooth pain you can call the doctor and go have a treatment. But here you have to call the doctor, you may not find the availability for the doctor. The doctor may not answer or do a lot of stuff for you. You have to go to the emergency room, they may not do anything for you.”

[2]: “I found it very difficult because it’s totally different. Here you have to sign, you have to check in, you have to wait, you have to get an appointment. Back home in Syria you just go in to the doctor.”

In terms of medication accessibility, many felt restricted by the U.S. prescription medication requirements. Participants preferred the system in Syria where medications were often accessed without prescriptions.

[4]: “Here is different. Like, you go to see your doctor, you cannot go to the pharmacy and get the medication. You have to see your doctor and they have [to]send that. They give you either the prescription or they will send the medication to the pharmacy immediately. In Syria, no you can get the medication from the pharmacy.”

One participant reported a lapse in treatment due to these requirements.

[5]: “In Syria, you can just go with the same medication, you can buy the same one without any prescription, anything, which is faster and easier. Here, if you are out of your medication, you have to call the doctor to refill it or anything, and here, many times, I have discontinued to have my medication because of the delay between the doctor responding or something I needed a prescription or refill it for me...Syria is better and faster because you just can go buy it and you are not going to be like missing your medication.”

In contrast, another participant admitted that the overuse of antibiotics she was accustomed to in Syria was likely harmful for her children. Despite frustration with her own providers in the U.S., she appreciated the added caution with pediatric care:

[3]: “I prefer the system here...only as far as of the kids and the treatment for the kids only, because in Syria...whatever the kids is sneezing, coughing we just go to the pharmacy, get an antibiotic, and like just treat them by our self. But here, they are very cautious about giving the kids antibiotics...That's why here they are helping the kids to have a stronger immune system and we were doing the opposite thing back in Syria...”

Direct access to specialty care was another aspect of accessibility where participants experienced limitations, though this was not unique to the U.S. health system:
[3]: “…in Jordan the circumstances and the conditions were different. They were difficult because of the financial problems, so if you want to go to specialist you have to pay or like you have the co-pays way more expensive than the general physician or the primary care provider. And we didn’t have any health insurance, whatever, like as a refugee they were helping us [but] it was not covering any Specialty Services…”

She went on to say:

[3]: “Here it’s very complicated…[in Syria] …you know I just like, if I’m like sick or if I feel something bad I can call the doctor he will tell me okay come after 1pm, I’m going to see you. But here, if I’m gonna to have something God forbid something happen to me I have to go get an appointment with the family doctor and it’s going to take a while to see the family doctor and then the doctor has to do a lot of stuff then finally I may get referred like to the specialist or no…”

While these and similar experiences saturated every interview, the findings are not dissimilar to the experiences of U.S. immigrants and immigrants to other higher-income nations.(53-55) However, a unique finding was an informal access to providers in Syria that was not experienced after arrival. In-depth interviews revealed that most participants had an informal relationship with a provider in the community (ie. family member, neighbor, friend, etc.) that allowed them immediate access to health advice and appointments.

[2]: “I had a friend who is a doctor too. And he’s actually my neighbor. So, he’s my friend, he’s a doctor, he’s my neighbor, and he has his clinic there…He was like the family doctor for myself, for my whole family…Many times even he was not examining me, just talking to me and seeing me because he knows me and he knows my health. He was giving me like couple of advices. “Go do this blood test. Go see this specialist, or anything. I’m gonna give you referral. I’m gonna talk to some people so they can let you in…”

[3]: “In Syria it’s different. If it’s like a simple emergency case, like my husband, so one time his blood pressure drop down so we went to the doctor that he’s like our neighbor. We just knocked on the door and we were there immediately.”

Sometimes these “connections” led to easier access or higher-quality care, though finances also played a role:

[4]: “…if you do not have a good financial situation, you know, so it is going to be hard because you have to wait and like to get an appointment and all that stuff. So either you have to have the money or you have to have the connections so that you can skip the row and you can go and get you know like you know the system… if you have the money and you have the connection you can do whatever you want because sometimes they postpone the people to have surgery or anything for different reasons, but if you have a good connection, you know the doctor, you are all set.”
Familiarity with the Syrian system of interactions with providers made the U.S. experience seem overly formal, translating into frustrations and perceived barriers with accessing care in a reasonable time frame. In fact, *timeliness of care* emerged as its own significant theme. Participants frequently described the frustration of waiting months for appointments with primary care providers and specialists in the U.S., along with lengthy emergency department wait times.

[1]: “In Syria when you go to the doctor, the doctor, like depends on your situation, they may give you treatment, like get pills or insulin, or anything that you needed like immediately. But here in the states if you have this problem like high blood sugar, if you want to get an appointment it’s going to be couple of months to get an appointment with your doctor if you’re so lucky or you have to go to the emergency room that you may stay one day or two days without doing anything.”

[5]: “And like here, I have been waiting more than 6 weeks for the yesterday appointment and all of a sudden, I went there it was a male provider and I have to wait another week to see my female doctor.”

Another participant with chronic disease co-morbidities echoed these experiences:

[2]: “The time and distance is very different and very hard here in the United States. Here you go see a specialist for example, I saw cardiologist or like a diabetes specialist. They give me the second appointment after one month or two months. But for example, here, I got more sick, tired, after three days. I can’t see the doctor. But back home in Syria, you see the specialist, you get like more sick in two days you can go again to see the doctor…”

**Clear Communication with Providers**

The current literature highlights communication as a recurring barrier for immigrants and refugees as they interact with foreign health systems and providers.(53, 55) These barriers also emerged as a major theme amongst our participants, where in-depth interviews revealed poor communication with providers related to language barriers and interpreter services. Participants emphasized the importance of using in-person interpreters and compatible dialects:

[2]: “…and here one of the most important thing is that you need an interpreter. The language is very very important because if you don’t have an interpreter you can’t communicate with your doctor.”
In addition, communication was also a problem when participants experienced vague communication regarding their diagnosis or felt dismissed regarding management of chronic complaints. One participant’s experiences summarized these feelings as well as the experiences of her peers:

> “[…my doctor here in the United States confusing me so much. In some appointments that he tells me you have Scleroderma and in other appointments he tells me you don't have Scleroderma so I'm really confused because they don't give me clear information…the last time I went to the doctor they told me thanks God that your blood test didn't show that you have scleroderma But the previous appointment I went there…they told me you have scleroderma, and I told them my doctor told me I don't have scleroderma and they told me no it's written in your chart that you have scleroderma.”

She went on to say:

> “Actually, to be frank with you I was a little bit healthier in Jordan and Syria more than here in the United States. My health got worse here in the United States…the problem here I go to the doctors, they asked me what's going on with you, I explain everything again and again, again and again, and I just go home without doing anything for me. They just told me, ‘It's okay, it's okay.’…it's bothersome for me because personally I am really frustrated and exhausted from this problem but they just say it's okay, it's normal, so I don't understand it…”

*Quality of Care:*

Many of the above experiences led to frustrations regarding the quality of care received in the U.S., as well as the perception that the care was lower quality or inadequate compared to Syria. In addition, they attributed these differences to a lack of diagnostic or treatment experience amongst providers. Participants often had chronic illnesses on arrival and were familiar with prior management strategies with which to compare current treatment. Others had chronic pain or long-standing complaints on arrival and experienced disruption in therapy due to formalities of medical practice in the U.S.:
[1]: “…back home in Syria, you may go to the problem for one time, he will give you the medication, and you may not see the doctor at all. You will be treated with the same medication that he gives it to you because he diagnose it very well and he knows the reasons for that. But here you have to come to the doctor once, twice, three times, four times, fifth times, even 10 times you may see the same doctor but they don’t know anything what they are doing.”

[2]: “…one of my doctors that’s managing my diabetes told me just stay away of carbohydrates. That’s different totally than my doctors in Syria. When you in Syria they diagnose you with some diseases, they tell you exactly, you know, you have to stay away from this, this, this, and you can eat one, two, three. So they tell you exactly from the beginning. But here, nobody’s told me, even I’m having diabetes, I’m having problem…”

[3]: “Actually, I know that my hand case, or my arm case, I have to continue having physical therapy continuously. I should like started once I came to this country, but I was telling the doctor every single time I am seeing my doctor, but he was telling me you have to be patient, you have to wait, we have many steps we have to do, we have routine things that we have to go before you could do physical therapy. And you now this postponing my physical therapy…”

One participants also questioned the quality of care he received while awaiting resettlement in Jordan:

[1]: If I wanna compare the medical system or the health system between Syria and Jordan I can say and I can count that for sure, Jordan, they don’t know anything about health system or anything at all in their lives…I went for the first time to a dentist and he extracted my tooth without numbing me. And the other one, I went to another doctor, he extracted my nail even though without numbing me…We had an experience that I had my niece…she was sick. We went to the doctors, many many doctors in Jordan, they couldn’t find anything. Even like we were telling them like they were examining doing lab tests, everything they were not giving any diagnosis. We just called one of our friends, family friends, he’s a doctor from Syria…we told him this is the symptoms and even over the phone he told us he has Familial Mediterranean Fever disorder…And he told us like this has a treatment you know but unfortunately they didn’t have the treatment available in Jordan.”

In contrast, a man whose child had special needs highlighted the organization and humanistic care of the U.S. health system compared to Syria:

[4]: “…here it is a little bit I think it is more organized and different because like we came to the country and after 2 weeks we had our like health card, insurance, everything was set up, our appointments, and they respect you. The doctor is very respectful, even like we are puncturing you with a needle or anything they keep like saying we are sorry or anything. It is a little bit more human into the side than the Syrian side…like we found everything that is really like helpful for us because we do not need to get any appointment or like, you know, run after the doctor to get appointments.”

His comments shed light on the Autonomy in Health Management that emerged from discussions on health maintenance in Syria. Participants described more independence in disease management and follow-up in Syria. They also reported consulting pharmacists for health advice instead of doctors or other clinicians:
[3]: “…this a huge, huge difference. You can’t compare. Because Syria we used to treat our kids by our knowledge, we just go get the medication that we know like from the pharmacy all that stuff.

[4]: “…but in Syria you got to have like general advice (especially at the last time in the war situation because we had less doctors and even the doctors they were like still in the country they were taking so much money, you know, or charging so much money if you see them)...A lot of people they were just going to the pharmacy if they need just like simple questions or a simple like prescription to get it from the pharmacist there.”

[5]: “…the difference is here, the people, here the health system, they follow you, and they give you appointments and you have to come. In Syria, you have to go and make a blood test or like do or ask your doctor to do that to follow that, the guidelines...It is not hard, but you do not feel that somebody is caring for you. Here, you feel different because they give you an appointment, they care about you…”

In terms of **Affordability and Coverage**, participants reported many difficulties with financing health expenses in nations of transition. They also described poor dental health and the high cost of dental care in the United States:

[3]: “…in Jordan the circumstances and the conditions were different. They were difficult because of the financial problems, so if you want to go to specialist you have to pay or you have the co pays way more expensive than the general physician or the primary care provider. And we didn't have any health insurance...like as a refugee they were helping us [but] it was not covering any specialty services.”

[3]: “Generally as a Syrians when we come here you know we have a like a bad teeth and a lot of teeth problems and unfortunately I'm one of these people that suffering from this problem, but the insurance is not covering anything...yeah it's like a barrier because fixing the teeth here is very expensive in the United States, because you have to extract and you can't like replace the teeth.”

One participant expressed the affordability of care in Syria, despite having to pay out-of-pocket:

[5]: “And even, in Syria, if you do not want to go to the community center or the government hospital just to wait for a couple of hours, you can go to any doctor you see or you know, like in the street [clinic], and they will just examine you immediately. They will see you immediately...This service was available in all Syria and it was very accessible and the pay or the expense was very cheap.”

**5.3 – Unexpected Shifts in Healthcare Delivery:**
Though participants arrived in the U.S. with specific healthcare preferences and values, they did not expect that these might not be compatible or taken into account with the U.S. healthcare delivery system. Individual accounts of these shifts in healthcare delivery upon arrival to the U.S. spoke to impediments related to: (1) Lack of Knowledge for Navigation, (2) Legal Limitations of the U.S. Healthcare system, (3) Evidence-Based Medicine, (4) Insurance Limitations, and the (5) Resident-run Clinic System.

Knowledge for Navigation:

While refugees are provided lectures, social workers, and supportive documents from resettlement agencies on adapting to life in the U.S., knowledge and support regarding the vast U.S. health system remains limited. Our participants reiterated these experiences as they described uncertainty about the U.S. healthcare delivery model.

While most participants understood how to make appointments and the process for receiving emergency care, knowledge of more nuanced aspects of the health system, including referrals and wait times between appointments were lacking:

[3]: “...I can't understand the system work here. How does it work the system here with the doctor, the diagnosis, the treatment, or anything like that...I can't understand why we have to go every single time to the family doctor to get a referral. Why we can't go to the specialist directly? It took me more than 5 months to get a referral to see the neurologist, and you know I have a neurologic problem, and I told them I have this diagnosis since 2 years, I already brought my medical charts...”

[5]: “You have to call. You have to see a family doctor. They will give you an appointment and you cannot see your specialty doctor unless a couple of months from now. I do not know what's the problem here. Do they have this much traffic as much like, you know, they do not have appointments to see the doctor or how does it work here? I don’t know.”

Limited knowledge of the system exasperated frustrations and prolonged already lengthy wait times to appointments:

[3]: “…even now I'm sick, I had to get an appointment with my family doctor. I get an appointment, finally he saw me and he told me, “No you should have seen your immunology doctor...follow up with your rheumatoid arthritis doctor...I call the rheumatoid arthritis doctor and I told him I'm sick, I really need to see you as soon as possible, They gave me an appointment in one and a half month from now.”
When asked about which information regarding the U.S. health system was lacking, one participant responded:

[5]: “Why the private doctors are very expensive and why we have to wait so much time to see the doctors.” She even remarked that more knowledge about the health system would help with expectations prior to arrival.

**Legal Limitations, Insurance Limitations, and Evidence Based Medicine:**

Although difficulty navigating the U.S. healthcare system was a predominant theme, participant accounts of access barriers often described limitations that were legal in nature or related to limitations of the Medicaid insurance plan. U.S. prescription drug laws, which differ from drug laws in Syria, prevent certain medications from being prescribed over-the-counter. (56) In addition, certain treatment regimens available in Syria may not be considered standard of care or approved for use in the United States.(57) In terms of health insurance, direct access to specialists is often a benefit of more expensive insurance plans, and many times insurers require that providers “prove” that a patient requires more expensive treatments or specialty services such as physical therapy. (58, 59) One participant articulated the regulation-based practice of medicine in the U.S.:

[2]: “…Here they have regulation for every single thing, they have regulation laws, but back home we don’t have this stuff about the health system.”

In terms of evidence-based medicine, providers in the U.S. may use different guidelines in management of chronic complaints or may prescribe first-line treatment regimens that a patient must fail prior to trying alternate therapies or specialty referrals. In addition,
chronic complaints may often be inexplicable, sequelae of chronic disease, or physical manifestations of psychological stress that can be difficult to treat.\(^{(60)}\) However, lack of adequate education regarding management for these chronic complaints may contribute to frustrations:

[3]: “...another thing I have itchiness. You know personally I have itchiness like in my genitalia and I've gone to the doctor numerous times and they just tell me it's okay, it's okay. There was only one time they gave me a pill and it didn't help and all the time I talk to them I go to the doctor and they say it's okay, but they didn't treat it at all.”

**Resident-run Clinic System:**

Finally, it is important to note that participants in our study were initially evaluated at a resident-run clinic and often referred for follow-up care to resident providers. While continuity of care for patients has been a challenge for resident clinics, the Yale Internal Medicine residents use the 4-1 block system, which can improve continuity but may create added barriers for acute-care visits.\(^{(61)}\) In addition, residents may have differing levels of experience in agenda-setting, difficulty acknowledging poor health literacy, and limited clinic resources.\(^{(62-64)}\)

### 5.4 – Impacts of Health System Deprivation:

As a result of unmet healthcare values and unexpected shifts in healthcare delivery, study participants reported an overall dissatisfaction with and mistrust of the U.S. health system. Our participants reported perceived barriers due to the formalities of the U.S. healthcare delivery model, with its legal limitations, insurance limitations, and practice limitations. Participants also experienced lapses in care and management as a result of unexpected changes in health access, poor communication with providers, and limited
knowledge of how to navigate the U.S. healthcare system. As a result, participants described a disinterest in attending clinic visits and a preference for herbal medicine and Prophetic Medicine practices:

[3]: “It's not only me. Most of the ladies here around me that I know the Syrians they have the same problem, they go to the doctor it's the same thing they don't treat them, so they just go back to use any traditional stuff or any herbal stuff that they know about.

These experiences are particularly difficult for participants with chronic illnesses and complaints as many had high expectations and even hopes for cure in the U.S. healthcare system. When asked about her expectations prior to arrival, the above participant lamented:

[3]: “I found it, it’s the biggest lie ever from all the aspects…Personally I accept to travel here. I could have denied or reject to travel to United States but I accept or we accept to come here just to have treatment, to be treated, to be cured with my illnesses in the United States.”
Chapter 6: DISCUSSION

Arriving refugees from the Middle East have a high burden of NCD morbidity and are at high risk for the development of these conditions, making them a population more likely to require chronic health services and comprehensive care on arrival.\(^{(2, 4, 6, 37, 65)}\)

However, the findings of this qualitative analysis reveal the variety of barriers to access experienced by Syrian refugee respondents, leading to delays in care, dissatisfaction, and for some, a motivation to disengage. Triggered by the unexpected formalities of the U.S. healthcare system, including prescription regulations, long wait times for appointments, and referral procedures, these experiences have been exacerbated by inadequate knowledge for navigation and barriers to communication. These findings are concerning as they reveal salient experiences of inaccessibility amongst a population with higher health needs on arrival.

While the current literature on refugee experiences with the U.S. healthcare system are limited, barriers to healthcare access and utilization amongst U.S. immigrants have been of longstanding concern.\(^{(53, 54)}\) A qualitative study by Mirza, et. al analyzed the responses of *key informants* in refugee communities, clinics, and aid associations on the healthcare access barriers of refugees with chronic conditions. Not surprisingly, they found similar findings regarding difficulties navigating the U.S. health system and barriers with communication.\(^{(53)}\) Though participants were not necessarily refugees, their comments shed light on the perspective of providers and support staff by highlighting their perceived system-level, provider-level, and individual-level impediments. For example, key informants in this study highlighted limited time for
health literacy during clinic visits, limited English language training, and limited resources for adequate interpretation as communication-related barriers. However, our work highlights the unique perspective of Syrian refugees from urban areas, whose communication-related concerns centered around vague communication from providers, feelings of dismissal, and a preference for in-person interpreters of the same dialect. These results emphasize particular provider-based shortcomings that suggest areas of intervention for improving access and engagement in care.

In terms of the complex health system, Mirza and colleagues revealed the inadequate collection of refugee health data during resettlement as perceived by key informants, along with limited provider knowledge to aid refugees in addressing their needs for disability services. While these perspectives shed light on the unique health needs of refugees with disabilities and chronic diseases, we document the unexpected challenges of Syrian refugees during transition to the U.S. healthcare system related to disengagement, such as issues with timeliness of care and frustrations with medication access. These challenges may be unanticipated by providers focusing on the general refugee health guidelines from the Centers for Disease Control and Prevention which favor infectious disease surveillance and immunization schedules. Moreover, they may be unaware of health systems in countries of origin or transition, or the high burden of NCD morbidity in those countries. (5)

Studies in other high-income nations have qualitatively analyzed the experiences of refugees and access to health systems, and corroborated our preliminary findings as well.
Hauger, et. al. studied Iraqi immigrants in Oslo, whose experiences of unmet expectations and distrust toward providers also supported our findings (Hauger, 2011). However, unlike the respondents in our study, these participants were of low socioeconomic status and preferred the health system in Norway over those of their home country. In comparison, our respondents often reported little impediments to access in Syria, with easy accessibility to specialists and services, suggesting they might be of a higher socioeconomic status. However, they also cited “connections” with providers as an alternative means of health access, though it is unclear if these connections were a byproduct of socioeconomic status.

Several studies on immigrant experiences in the U.S. and refugee experiences abroad emphasize the challenges of adapting to a new culture and navigating it’s health system, often citing language and health literacy as dominant features of these barriers.(53-55) While these studies support our findings regarding communication and difficulty with navigation, unfortunately, much of this literature focuses on diverse groups of immigrants, limiting the ability to unmask the unique health needs of any one population.(53) In addition, the dearth of qualitative literature in the U.S. examining the perspectives of refugees as they adapt to the U.S. healthcare system further limits the ability of the current literature to define and address gaps leading to decreased access.

Our analysis provides insight to the experiences of adult Syrian refugees, many with chronic illnesses, after arriving from a middle-income nation where respondents reported ease of accessibility to healthcare through financial means, “connections” to providers,
and fewer legal limitations. This experience may differ substantially from experiences of migrants arriving from poor health systems with limited accessibility, especially those with many years spent in camps, unlike our sample, and who may not be accustomed to larger health systems of care delivery (Hauger, 2011). For refugees arriving from nations with intact health systems, expectations for healthcare delivery may differ, and patients may struggle with the unexpected barriers and added hurdles that differ from their home country. Our analysis suggests a greater need for navigation support for newly arrived refugees, including thorough explanations of system processes that may differ from those of their country of origin, including referrals and prescription drug access.

In addition, we examined and uncovered limitations in refugee-provider interactions that may contribute to disengagement of care. Respondents in our sample with chronic diseases or complaints felt dismissed by providers, experienced neglected health needs, and described uncertainty and frustration about management. These results suggest the importance of communicating with appropriately-matched interpreters, agenda setting, and thoroughly addressing the variety of patient complaints so as to prevent disengagement.

Though many studies highlight access barriers of migrants related to language and system navigation, our work defines the specific aspects of these barriers that are most distressing and concerning from the perspective of Syrian refugees, and identifies key areas for intervention and further study. In addition, our work highlights the potential impact of access barriers (ie. delays in care, mistrust, dissatisfaction, reliance on
traditional medicines, etc.) that underscore the importance of accessibility for these individuals, and stresses modes of intervention.
Chapter 7: LIMITATIONS

Study limitations include the multiple participants in our study that were related, which may have contributed to the congruency of the themes that arose. This could not have been avoided due to the small size of the newly arrived Syrian refugee population between September 2016 and March 2017. There were four husband and wife couples and one set of four siblings, however, we expect that the variety of experiences from differing genders, education levels, occupations, and ages provided rich and in-depth insight into the Syrian refugee experience. Another confounding variable was the status of our co-investigator, AA, who was well-known to the Syrian refugee community, and one of two in-person Arabic interpreters in the Yale New Haven Health system. Potential bias may have been introduced by his close connection and familiarity with the participants. Due to the valuable language services he provided during patient visits, participants may have avoided criticism of in-person interpreter services. In addition, as a former general surgeon in Syria, participants may have spoken more positive about the Syrian system due to his association. While his involvement in recruitment likely accounted for more participation than may have been obtained otherwise, his presence allowed for candid and detailed accounts of negative experiences which can often be a limitation in the study of migrants.
Chapter 8: IMPLICATIONS

To our knowledge, this is the first qualitative study to analyze and understand the transition between health systems and models of healthcare delivery for newly arrived refugees, and its impact on refugee health and experiences with the healthcare system. As the current literature on the access barriers experienced by refugees is limited, we provide a roadmap to addressing potential challenges for refugees as they encounter the U.S. healthcare system, particularly those arriving with prior healthcare system experiences. Healthcare providers working with Syrian refugees should focus on clear communication and health education, particularly with regard to chronic complaints and chronic disease management, appropriate interpreter services, and timely referrals to specialty care and services. Social support staff for refugees might consider more in-depth orientations to the U.S. healthcare system, including prescription drug processes, referral processes, and limitations of the Medicaid health insurance plan. In addition, our work suggests the need for further examination of refugee experiences with respect to access barriers, and possible quantitative analyses of system barriers for refugees with non-communicable diseases.
References:


66. Hauger, J., *“We Expected Paradise”: Iraqi Immigrants’ Perceptions and Experiences with Healthcare in Norway*, in (Master’s Thesis). Oslo Department of Community Medicine, University of Oslo. 2011.


APPENDIX A: RECRUITMENT SCRIPT

Hello,

My name is Eunice Martins/Amer Abdullah. I am a medical student/Syrian physician and researcher who is conducting research on the health of Syrian refugees, specifically as it relates to Diabetes. I am asking you to participate because you are a member of the Syrian refugee community in New Haven; your knowledge and perspective is valuable in helping us to understand the community.

There are many differences in lifestyle and health maintenance between the U.S. and Syria. I am hoping to understand the specific health knowledge and practices amongst Syrian refugees so that providers in the U.S. can better care for them.

In this study, I will be conducting one-on-one interviews with each participant and an interpreter, and will be asking questions about diabetes and health-related practices. This is not an assessment and we are not evaluating you. We simply want to know about all you have heard and believed about diabetes and healthcare providers. Each interview will be no longer than 1 hour and will be located at Yale School of Medicine.

Each participant will receive a 20$ gift card to a local grocery store for their time.

If you have any questions or would like to participate in the research, please call back at 201-780-3091.
APPENDIX B: INTERVIEW GUIDE (67-73)

1. Do you think you are healthy right now? Why/why not?
   a. How is your health in the U.S. different than in Syria?
   b. What did you do to maintain your body’s health in Syria?
      i. How did this change when the war started? When you fled to…?
         1. Why did/didn’t it change?
      ii. What has changed since coming to the U.S.?
      iii. What are the things that made the experiences different?
      iv. Does exercise matter/physical activity matter?
         1. How did this change after you arrived in U.S.?
         2. What gets in the way of you being physically active now?
   c. What barriers made it difficult to be healthy or prevent sickness in Syria?
      i. What about in the U.S.?
   d. What health behaviors did you notice in other Syrian refugees? What was positive? What was negative?
      i. What about here in the U.S.?

2. Tell me what your diet is like now? – What is a typical meal for you?
   a. How is that different from your diet in Syria?
   b. What changes did you make to your diet when the war began?…When you fled to …?
   c. How often do you eat western fast food in the U.S.?
   d. Have you noticed any changes in your weight since you came to the United States?
      i. How do you feel about those changes?
      ii. Have those changes affected how you eat? Or how active you are?
   e. How could your diet be better than it is now?
   f. When it comes to maintaining a good diet and a healthy weight – does cost matter?
   g. When it comes to maintaining a good diet and a healthy weight – where do doctors/healthcare providers fit in?
      i. Do they matter?
      ii. How might they help

3. In your experience, what does diabetes mean to you (What’s the first thing that comes to your mind)?
   a. What do you think of the name for the disease – “Diabetes?” How do you feel about that term?
   b. Do you know anyone with diabetes?
      i. What does having diabetes mean to them?
   c. How might someone become diabetic?
      i. In your experience, what other things can make someone diabetic?
      ii. Do emotions play a role in someone becoming diabetic?
         1. How?
   d. Can you describe the person that is diabetic?
      i. Does weight matter?
      ii. Does age matter?
      iii. Does income level matter?
      iv. Does their anxiety level/temper/personality matter? How/why?
   e. Do you know how diabetes affects the body?
      i. What are the complications?
      ii. Is healing a problem?
   f. How can you someone tell that they have diabetes?
      i. If you had diabetes, how would you feel? In your mind? In your body? Why?
      ii. In your opinion, what places you at risk for getting diabetes and why?
      iii. Do you think there differences between how people think about diabetes in Syria vs. the US? Why?
g. In your experience, how do doctors help people manage diseases like diabetes?
   i. Is it necessary to see a doctor? Why/Why not?
   ii. What experiences did your (friend/family) have with doctors when they found out they had diabetes?
   iii. In your experience, how did they feel about testing their blood sugar?
      1. Did the frequency matter?

h. In your experience, is there any aspect of having diabetes that is especially difficult for Syrian Refugees

4. In your experience, what things can prevent diabetes?
   a. Is that what you do? Why/Why not?
      i. What do you do to prevent diabetes/progression/complications?
      ii. What do your friends/family members with DM do?
   b. In your opinion, is this easier/harder in the U.S. vs. Syria?
   c. Different cultures have different feels whether it is better to be a heavier weight or lighter. Do you think there’s anything in Syrian culture that speaks to this concept? How is this different than the US?
   d. In your experience, are there foods that you would avoid to prevent diabetes? How?
      i. Sweets – what kind?
         1. Does rice matter? What do you think about rice?
            a. Why do you eat rice so often/little?
            b. How do you think rice affects your health? Why?
         2. Does fruit intake matter?
      ii. How is that that different (easier/harder to prevent diabetes) from when you were in Syria?
   e. Can drinks impact your diabetes?
   f. What are some things you might do, in addition to eating healthy foods, to prevent diabetes?
      i. Does exercise matter? Why? Why not?
      ii. In your experience, how does diabetes prevent you from being physically active/exercising.
   g. In your experience, what is a healthy diet?

5. What do you think might be some things a doctor would tell someone to do when they have diabetes?
   a. What are some of the things you’ve heard family and friends say about diabetes, about what you should do if you have it?
      i. Anything different from what a doctor might recommend?
   b. What else have you heard people should do when they have diabetes?
   c. Tell me about the ways you or your friends/family members would manage diabetes?
      i. What do you think are the medications for diabetes?
         1. In your opinion, what will happen if they don’t take the medications/treatments?
            a. In your experience, how will that affect your body or your lifestyle?
         2. Did you know that your body makes insulin? Is there a difference between the insulin the body makes and the insulin doctors prescribe?
      ii. Do you know anyone who has been treated or cured from Diabetes?
         1. What did they think about it?
   d. In your experience, are there any cures for diabetes that a doctor cannot provide?
   e. If you had diabetes, what would make it difficult to treat/cure?
   f. Do you think living in Syria would make it easier (or harder) for someone to manage their diabetes? Why?

6. Who do you speak to or Where do you go when you need health advice? Why?
   a. Is there anyone else in the U.S. that you might see for health advice instead of seeing a doctor/nurse?
      i. If friends – in Syria, who would you go to more often: doctors or friends? Why?
   b. How often would you see a healthcare provider in Syria? Why?
i. Were those positive experiences? Negative? Tell me about your experiences.

c. Did you know a doctor informally? In your family or a neighbor or a friend?
   i. How did this play a role in your medical care/health advice?
   ii. When did you seek formal care? When did you go to a doctor friend/family member?

d. What was it like to see a provider in the U.S. for the first time?
   i. What were your expectations?
   ii. Were there any disappointments?
   iii. Why do you believe wait times are so long in the U.S. (if they bring this up?)
   iv. Why do you believe it’s hard to get prescriptions (antibiotics) here?

e. In your experience, if you had an emergency or a health concern, what would be the process for you to get care in the U.S.?
   i. How do you navigate the health system here? How is that different than at arrival?
   ii. What knowledge about the system here do you feel you are missing?

f. What do you miss about the healthcare system in Syria?

g. How have doctors been helpful to you?

h. What are the things that you didn’t like about the healthcare system?
   i. In Syria
   ii. In the U.S.
      1. How does the legal system/regulations here create barriers to your access to health?
   i. How does being a refugee impact your experience with doctors/clinics/hospitals?
   j. In your opinion, are there things doctors should do in the U.S. that they haven’t done. Why?
      i. Should doctors do anything different when they encounter Syrian refugees?
      ii. Why should they do it?
      iii. Why do you think they didn’t do it?

k. How do you think the health system here could better serve Syrian Refugees? What do you suggest

7. In your religious texts or ideals, are there any practices on health that you apply?
   a. Does it comment on treatments that you consider/how you engage with treatments/pills?
   b. Does it comment on doctors? Does it impact the way you view doctors? Interact with them?

Thank you so much for your time!
APPENDIX C: CODEBOOK

1. Culture Shock
   a. Language
   b. Food Culture
   c. Social Interactions/Relationships
   d. Lifestyle Changes
      i. Time Constraints (+/-)
      ii. Financial Stressors (+/-)
   e. Shifts in Healthcare Delivery
      i. Perceived Inadequacy of Care
      ii. FeelingDismissed by Doctors
      iii. Knowledge for Navigation
   f. War

2. Health Beliefs/Practices
   a. Sources of Health Beliefs
   b. Dietary Beliefs/Practices
   c. Health Behaviors
      i. Weight Changes
      ii. Smoking
      iii. Physical Activity
   d. Psychology and Health
      i. Psychological Impact of Diabetes (should probably just keep as Illness Psychology as below…)
   e. Prophetic/Traditional Medicine
      i. Fasting/Detox
      ii. Herbal Medicine
   f. Chronic Illness Experiences (unsure whether to make this Illness or Diabetes, but some quotes aren’t about diabetes so I kept Illness for now and merged it will the chronic medical problems codes)
      i. Illness Severity
      ii. Illness Suffering
      iii. Illness Associations
      iv. Illness Causes
      v. Illness Management
         1. Blood Sugar Control
      vi. Illness Psychology
      vii. Illness and Faith

3. Healthcare Values
   a. Timeliness of Care
      i. Informal Access to Providers
   b. Ease of Accessibility
      i. Barriers Due to Formal USHCS
      ii. Direct Access to Specialty Care
      iii. Medications Access
      iv. Informal Access to Providers
v. Discordant Gender

c. Quality of Care
   i. Frustration with Unsatisfactory Care

d. Clear Communication
   i. Language

e. Self-Management/Autonomy

f. Affordability/Coverage
Syria Physiography. The country of Syria is outlined in the center of the map. The cities of origin from which participants were recruited are highlighted in yellow. From top to bottom: Hamah, Homs, Damascus, and Dar’a. These cities lie close to the borders of Lebanon and Jordan. Countries in which participants awaited resettlement are highlighted in green. From top to bottom: Turkey, Lebanon, Jordan.
Figure 1: Syrian Refugee BMI Data. BMI data from the domestic medical evaluation in the electronic medical record are compared to subjective pre-arrival BMI’s and the last recorded BMI’s in the electronic medical record. Subjective BMI’s are comprised of the participant’s subjective estimation of their pre-arrival weight combined with height data from the electronic medical record. Arrows imply an increase or decrease compared with the BMI at the domestic medical evaluation. “Change in BMI” implies the difference between the first and last recorded BMI.
APPENDIX F: ADDITIONAL THEMES

Figure 2:

Core Emerging Themes

What are the experiences, beliefs, and practices regarding general health, healthcare delivery, and Type 2 Diabetes amongst newly arrived Syrian refugees at VNH.

<table>
<thead>
<tr>
<th>Relationship Between Food and Health</th>
<th>Theme #1: Culturally informed beliefs and practices around food shape understanding of the relationships between food and health.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare System Deprivation</td>
<td>Theme #2: Unmet expectations for healthcare delivery and patient-provider interactions lead to experiences of perceived healthcare system inaccessibility and insufficiency.</td>
</tr>
<tr>
<td>Illness Psychology</td>
<td>Theme #3: Cultural beliefs about psychological and emotional stress influence understandings of disease etiology, and prevention and management strategies.</td>
</tr>
<tr>
<td>Chronic Illness Experiences</td>
<td>Theme #4: Individual chronic illness narratives permeate social networks to shape a specific set of shared knowledge, attitudes, beliefs, and behaviors.</td>
</tr>
</tbody>
</table>

Figure 2: Emerging Themes. The four major themes emerging from the preliminary analysis of five transcripts are outlined.

Figure 3:

Emerging Themes and Sub-Themes

What are the experiences, beliefs, and practices regarding general health, healthcare delivery, and Type 2 Diabetes amongst newly arrived Syrian refugees at VNH.

Figure 3: Emerging Themes. The major emerging themes related to the research question and their associated sub-themes are shown above. Arrows indicate the conceptual relationships between themes and sub-themes.
Figure 4: The Relationship Between Food and Health. Discussions related to health maintenance, diet, and disease management revealed the above interrelated themes. Participants described food as a toxin when discussing the U.S. food culture. The medicinal use of food involved herbal medicine and prophetic medicine.

Figure 5: Illness Psychology. Discussions regarding illness etiology, prevention, and management revealed themes related to the psychological impact of disease. Intense emotional states were described as a cause of disease. Participants also referenced emotional states in discussions regarding disease prevention and management.
Figure 6: Chronic Illness Experiences. Discussions regarding health maintenance and diabetes revealed themes related to chronic illness, including etiology, morbidity, and management. Participants also discussed other complaints and comorbidities, as shown above.

Figure 7: Healthcare System Deprivation. Discussions related to experiences with healthcare systems and models of delivery revealed the experience of healthcare system deprivation. Unexpected shifts in healthcare delivery led to unmet healthcare values and difficulty accessing care.