

The Ethics of Prevention:

Counseling, Consanguinity,
and Premarital Testing for
Beta-Thalassemia in Jordan

by

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Dedication

To my parents

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Contents

Dedication	1
Acknowledgements	2
Contents	3
Introduction	4
1. Welcome to the Kingdom: A Primer on Jordan	8
2. Thalassemia: Incidence, Cost, and Treatment in Jordan	19
3. Consanguinity in Jordan: A Challenging Tradition	30
4. Reinventing the Wheel? The Prevention Program for Beta-thalassemia in Jordan	41
5. The Ethics of the Prevention Program	71
Conclusion	86

Dedication	1
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Bibliography	90
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Introduction

The first floor of the health center was packed. In the Amman comprehensive health clinic, hundreds of people, patients and their families, filled the reception area, creating a frenetic atmosphere. Bells rang constantly, signaling the calling of another ticket number. It was December 2010 and as Bassem, one of the Ministry of Health officials later explained, the clinic was especially crowded this Thursday as everyone was hoping to see their doctors before the weekend. I managed to find my way to the stairs and to one of the upper levels of the clinic where I found the genetic testing center. This small office, one of many across the country, is where key parts of the Jordanian prevention program for beta-thalassemia are being carried out.

In the office, I was able to speak with Huda, a Ministry of Health doctor and general pediatrician by training. Huda, like many of her Jordanian counterparts, is forced to act as an ad hoc genetic counselor for the program. Despite her lack of formal training, Huda counsels couples who are both carriers for beta-thalassemia on whether to pursue marriage. In reflecting upon the national program, and the cases when couples split, Huda provided an important insight: “Medicine have to help people, not to make their life more in trouble.” This statement reflects one of the six basic principles of medical ethics: non-maleficence, or do no harm. Public health aims to incorporate non-maleficence, as well as beneficence, the principle of helping others, on a population level, aiming to improve the health of the community.¹ Instituted in 2004, the premarital prevention program is an attempt by public health officials in Jordan to reduce the burden of beta-thalassemia on

¹ Kass, “An Ethics Framework,” 1776.

society. It is unclear whether the initiative manages to follow Huda's instructions and adhere to wider ethical standards of not making patients' lives "more in trouble."

Genetic screening programs represent an important, new frontier for public health. In this thesis, I critically assess the specific case of the premarital prevention program for beta-thalassemia in Jordan. The first attempt at preventing genetic disorders in the country, it represents a significant step by the government to reduce the burden of an incredibly expensive disease. Thalassemia is the most common single-gene disorder in the world and has a disproportionate presence in the Eastern Mediterranean region.² It is just one of the many genetic diseases that has become of increasing importance in the Middle East as economic development has reduced the impact of infectious diseases and infant mortality.³ In Jordan specifically, the beta-thalassemia variant has a tremendous economic and health cost. Patients suffer through a life-threatening anemia that requires frequent blood transfusions and invasive iron chelation therapy. The average life expectancy for those affected with beta-thalassemia major, the most severe form of thalassemia and the focus of this program, is only thirty-two years.⁴ In Jordan, the government provides treatment free of charge for all citizens affected by beta-thalassemia and thus devotes a significantly disproportionate amount of resources to the disease; it spends over sixty times what it spends per capita on healthcare to treat one patient with

² Tadmouri et al., "Blood Disorders," 1.

³ Hamamy et al., "Communities," 59.

⁴ Strauss, "Genetic Counseling for Thalassemia," 367. I should note that throughout this thesis, when I refer to beta-thalassemia, I am referencing beta-thalassemia major.

beta-thalassemia major.⁵ This initiative represents a major priority for public health in the country.

In this thesis, I evaluate the Jordanian prevention program, paying special attention to possible ethical implications. I begin in chapter one with an introduction to Jordan, focusing on its history and health demographics, providing an important grounding to understand the context of the program. Then, after discussing the biology, burden, and treatment of beta-thalassemia in Jordan in chapter two, I move into a discussion of consanguinity in chapter three. Consanguineous marriages are an extremely prevalent tradition in Jordan and represent one of the main factors in the high incidence of beta-thalassemia. The chapter on consanguinity addresses the apparent social benefits of the tradition as well as the clear health costs, while attempting to avoid common Western biases against the practice.

In chapter four I discuss the specific structure of the beta-thalassemia prevention program in Jordan. My analysis makes use of comparison between similar initiatives in other countries, specifically the programs in Cyprus and Iran. Interviews with Jordanian doctors, lab technicians, and public health officials, provide important revelations about the difficulties surrounding the program, specifically regarding abortion and the quality of genetic counseling. These are key factors to consider, especially when assessing the program on an ethical, not just financial or statistical, level. The fifth and final chapter is devoted to an evaluation of the ethics of the Jordanian program. I focus on two specific issues: nondirectiveness in genetic counseling and the effect on consanguineous marriage.

⁵ Jordanian Ministry of Health, *Annual Statistics Report*, 3.

These are not the only two ethical difficulties surrounding the program. Nevertheless, in examining these, it is possible to gain important insights of wider ethical significance. This is especially true as there has been no recognition in the literature on the possible impact of genetic screening programs on consanguineous marriage. Finally, I conclude with a summary of the thesis as well as a brief suggestion for how the Jordanian program, and similar initiatives, can move forward. Given the increasing importance of genetic screening across the world, as well as the presence of similar initiatives across the Middle East, these considerations are particularly urgent.

Throughout this thesis, I feature the perspective of the urban, Jordanian medical elite, in an attempt to gain some qualitative insight into popular attitudes towards consanguinity and the program as a whole. To preserve the confidentiality of all of my informants, I use pseudonyms throughout this work. Most of these interviews were conducted during my fieldwork in the country in December 2010. Some of these contacts were established in the summer before when I became interested in the topic while working in Amman.

Chapter One - Welcome to the Kingdom: A Primer on Jordan

Background

After World War I, the area currently known as Jordan was placed under British mandate and given the name Transjordan. It gained its independence from Britain in 1946 and assumed the title of the Hashemite Kingdom of Jordan in 1950. Jordan is a constitutional monarchy with a representative government and the Hashemite dynasty has maintained control over the country since its inception. The current monarch, the Western-educated King Abdullah II (born 1962), serves as the head of the state, chief executive, and commander of the armed forces. He took over from his father King Hussein (1935-1999) in 1999, who himself succeeded his father King Abdullah (1882-1951), who was assassinated in Jerusalem in 1951.

Economically, Jordan is one of the smallest players in the Middle East. This is due to a paucity of natural resources, specifically a lack of water, oil, and natural gas. Over eighty percent of the land is considered to be semi-desert.⁶ The result is that the Jordanian economy relies on foreign aid, remittances from abroad, and the service industry; only twenty percent of the labor force works in industry, and less than three percent in agriculture.⁷ The country boasts one of the best literacy rates in the Middle East at 89.9 percent.⁸ Nevertheless, unemployment in the country is officially estimated to be just

⁶ Dasouki and El-Shanti. "Genetic Disorders in Jordan," 325.

⁷ Ibid., 326.

⁸ Central Intelligence Agency, "The World Factbook."

under thirteen percent; unofficial estimates put the number at around thirty percent.⁹ In 2009, Jordan's GDP per capita of \$5,100 placed the country at number 144 in the world.¹⁰

Islam is the official religion of the kingdom. Over ninety percent of the Jordanian population is Sunni Muslim and the ruling family traces its lineage, and thus part of its legitimacy, to the Prophet Muhammad.¹¹ The "natives" in Jordan are made up of those who have lived in settled villages and towns throughout the country for centuries as well as the Bedouin tribes.¹² These tribes form an important part of the political and economic structure in Jordan. Extended kin relations also serve a key role in defining individual social identity.¹³ During the late nineteenth century, many Circassians were forced to emigrate by an expanding Russia and over a million of them settled in the then Ottoman Empire, including Jordan.¹⁴ Estimates of the number of Circassians in Jordan range from twenty to eighty-thousand.¹⁵ There also exist small numbers of Armenians, Kurds, Chechens, and Gypsies. More recently, Palestinian and Iraqi refugees have flooded the country. The latest influx of approximately four hundred and fifty-thousand Iraqis into Jordan may have long-term effects on the country.¹⁶ However, the considerable presence

⁹ Ibid.

¹⁰ Ibid.

¹¹ Ibid. There is also an important indigenous Christian minority in the country. During my time in Jordan, I witnessed many public celebrations of Christmas. Although most stores were not closed, in the days before and on the holiday many individuals roamed the streets dressed as Santa Claus, ringing bells

¹² Hamamy et al., "Communities," 53.

¹³ Ibid.,

¹⁴ Brand, "Palestinians and Jordanians," 47.

¹⁵ The Royal Hashemite Court, "The People of Jordan."

¹⁶ UNHCR, "UNHCR - Jordan."

of Palestinians in Jordan has already had a clear influence on Jordanian culture and identity.

The declaration of the state of Israel in 1948 resulted in the migration of over seven-hundred thousand Palestinians, seventy-thousand of whom crossed directly over the Jordan River to the East Bank and the land then known as Transjordan.¹⁶ Today it is estimated that almost forty percent of the population in Jordan is of Palestinian origins.¹⁷ Palestinians account for a large part of the increase in the total population in the kingdom from half a million in 1952, to around six and a half million today.¹⁸ The dramatic increase of Palestinians has led to friction within the country between those who are “Transjordanian,” more specifically from the Arab Bedouin tribes associated with the government and military, and the “Palestinian-Jordanians.” As international relations scholar Laurie A. Brand points out, the existence alone of different subethnic groups is not sufficient for the development of problems.¹⁹ However, certain political maneuvers over the past sixty years, specifically Abdullah’s annexation of the West Bank in 1950, the Palestinian coup attempt in 1957, and the fighting between the Palestinian Liberation Organization, or PLO, and the monarchy in 1970-1, have contributed to the development of a culture of distrust between the two groups. These tensions are clearly present today.

In July 2010, a powerful group of ex-army officials sent an open letter to King Abdullah II, decrying the Palestinian occupation of Jordan. In the letter, a rare example of

¹⁶ Brand, “Palestinians and Jordanians,” 47.

¹⁷ Fisk, “Why Jordan is Occupied.”

¹⁸ Dasouki and El-Shanti, “Genetic Disorders in Jordan,” 326.

¹⁹ Brand, “Palestinians and Jordanians,” 52.

public criticism of the monarch, the authors declared the government had shown 'extreme weakness' towards Israel and America and unfairly granted citizenship to many Palestinians.²⁰ This bias against Palestinians runs strong in the government and armed forces. An "East Banker first" trend emerged in the 1970s of preferential recruitment for Transjordanians into the bureaucracy.²¹ This, combined with the influx of Palestinian capital from the Gulf, has created a dramatic schism between the public and private sectors along ethnic lines.²²

To further preserve loyalty to the monarchy, Abdullah and Hussein recruited certain tribes to become part of the state apparatus.²³ The government also instituted a one-person, one-vote system which encourages people to vote for single representatives from their tribe.²⁴ Perhaps in response to pressures like those mentioned above, the government arbitrarily withdrew the citizenship of over twenty-seven hundred Palestinians living in the country between 2004 and 2008.²⁵ These individuals were not given any official notice; they simply found out that they no longer had Jordanian citizenship while completing routine tasks at government offices.²⁶

Tensions erupted again in December 2010 after a football match between supporters of the Al-Wehdat and Al-Faisali clubs. The Al-Wehdat club is located in the

²⁰ Fisk, "Why Jordan is Occupied."

²¹ Brand, "Palestinians and Jordanians," 53.

²² Ibid., 53.

²³ Ibid., 48.

²⁴ Ibid., 60.

²⁵ Human Rights Watch, "Jordan."

²⁶ Ibid.

Amman New Camp (known locally by the same name as the club), the largest Palestinian refugee camp in the world. Supporters of the club, mostly Palestinians, clashed with those of Al-Faisali club, who are mostly Transjordanians, leaving two hundred and fifty injured.²⁷ The violence happened after Al-Wehdat beat Al-Faisali 1-0 in a critical game in the country's national football league.²⁸ This is not the first instance of outbursts at games; during a match last year, Al-Faisali supporters chanted about the Palestinian origin of King Abudllah's wife, Queen Rania (born 1970), another rare public criticism of the royal family.²⁹ These instances of public dissent underline the clear importance of this issue to many people in Jordan.

In my personal interactions with Jordanians, spread out over three visits to the country, I have seen a range of responses to these questions over national identity. Some are quick to cite the fraternal nature of the Palestinian-Jordanian relationship, while others are steadfast in their attachment to a single identity. At the University of Jordan Medical School, I spoke to an Oxford-trained microbiologist called Marwan. When I asked Marwan about these issues of identity, he explained that he rarely paid attention to these issues: "I've had research assistants in my lab for years and I honestly don't know their backgrounds. I don't know and I don't care." Marwan's own family is originally Palestinian. However, he pointed to his walls where he had two wall hangings: "I have Petra and Jerusalem as an example...I belong to both. I don't make a difference between them." Not all Jordanians, however, are as quick to overlook differences and it is

²⁷ Associated Press, "Jordanian and Palestinian Soccer fans Clash in Amman."

²⁸ Ibid.

²⁹ Ibid.

important to be aware of these cultural tensions, especially when considering the role of the government in regulating personal behavior.³⁰

Camila 9/29/11 11:54 PM
This seems a little vague...
would it be weird to be more
specific and say
“reproductive behaviour” or
family planning or some
other term that would be
more appropriate?

Health and Healthcare in Jordan

Jordan compares well with other countries in the region in health metrics: it ranks tenth in infant mortality at twenty-two deaths per thousand; fifth in maternal mortality at forty-one per hundred thousand live births, and first for prenatal care coverage, as ninety-one percent of women receive at least four prenatal care visits.³¹ In 2009, life expectancy for males was 71.6 years and 74.4 years for females.³² The government devotes a substantial portion of its budget to health; it accounted for eight percent of total governmental expenditure in 2009.³³ Healthcare is provided in Jordan through a variety of different media.

The Ministry of Health operates over fifty comprehensive healthcare clinics, nearly three hundred and fifty primary healthcare centers, and twenty-nine hospitals.³⁴ This is in addition to the ten military, two university, and fifty-six private sector hospitals in Amman and the major cities.³⁵ The ratio of physicians to citizens is 22.4 to 10,000 in the country, and 32.5 to 10,000 for nursing and midwifery personnel.³⁶ There has been no

³⁰ This is a particularly important consideration given the ethical assumptions underlying public health programs and especially attempts at genetic screening.

³¹ Halasa, “Mapping Healthcare Financing,” 39.

³² Dasouki and El-Shanti, “Genetic Disorders in Jordan,” 327.

³³ Jordanian Ministry of Health, *Annual Statistics Report*, 3.

³⁴ Hamamy et al., “Communities,” 52-3.

³⁵ Ibid.

³⁶ Ibid., 53.

serious study of the quality of healthcare in Jordan.³⁷ However, the country's status in the region as a destination for medical tourism suggests a certain level of quality and expertise.³⁸ This highly specialized care is not accessible to all Jordanians.

Nearly three quarters of the Jordanian population possesses at least one form of health insurance.³⁹ The largest of the providers is the Royal Medical Service, which offers coverage for the military, public security and civil defense officials, as well as their dependents.⁴⁰ It is followed by the Ministry of Health (24.6 percent), the United Nations Relief and Works Agency which serves Palestinian refugees (10 percent), private firms (9.2 percent), and university hospitals (1.4 percent).⁴¹ Yara Halasa, a health policy research associate at Brandeis, explains that the Ministry of Health is seen as the "implicit insurer of last resort."⁴² This is because it provides universal coverage, allowing access to its facilities at highly subsidized fees.⁴³ Notably, this includes comprehensive primary and secondary care coverage for the poor and uninsured as well as treatment for HIV/AIDS, cancer, and rare blood diseases (including thalassemia) for the whole population.⁴⁴ The coverage provided by the Ministry, however, is limited.

³⁷ Ibid.

³⁸ Ibid.

³⁹ Halasa, "Mapping Healthcare Financing," 9.

⁴⁰ Ibid., 16.

⁴¹ Ibid., 9.

⁴² Ibid., 10.

⁴³ Ibid., 11.

⁴⁴ Ibid.

The Ministry of Health facilities have been consistently underfunded and its officials lack the skills and medical technologies needed for advanced treatments.⁴⁵ Furthermore, the Ministry's health insurance program, despite essentially having no premiums, can still be cost-prohibitive for the poor.⁴⁶ This is due to the fifteen to twenty percent copayments associated with treatments.⁴⁷ There is no limit on the out-of-pocket expenses one has to pay, meaning that the poor are left with no protection from catastrophic illness.⁴⁸ These types of deficiencies are especially pronounced in genetic services.

Genetic services were first established in Jordan with the creation of a cytogenetics laboratory at the University of Jordan in the late 1980s.⁴⁹ This was also the site of the first clinical genetics clinic in the country, which began in 1992 and lasted for a short period.⁵⁰ A similar clinic and cytogenetics laboratory were founded in 1994 at the Jordanian University of Science and Technology and were open for ten years; today only the laboratory still survives.⁵¹ According to doctors Majed Dasouki and Hatem El-Shanti there is not a single board-certified clinical geneticist practicing in Jordan.⁵² This was confirmed by my experience. I was informed that two clinical geneticists were practicing

⁴⁵ Ibid., 10.

⁴⁶ Ibid., 11.

⁴⁷ Ibid.

⁴⁸ Ibid.

⁴⁹ Dasouki and El-Shanti, "Genetic Disorders in Jordan," 327.

⁵⁰ Ibid.

⁵¹ Ibid.

⁵² Ibid.

at a clinic at the Jordanian University of Science and Technology. However, upon arrival at the clinic I found that one was not actually a clinical geneticist (instead a biochemical geneticist) and the other had returned to America to finish her board certification. There is, however, a scattering of Ph.D. level molecular geneticists and cytogeneticists who have trained abroad, as well as some who have trained in Jordan.⁵³ This is in addition to a few in vitro fertilization (IVF) clinics at private hospitals.⁵⁴ Nevertheless, there is a clear paucity of genetic services, especially counseling. Given the increasing prevalence of genetic diseases, this lack of resources puts the country and its nascent prevention efforts at a severe disadvantage. A report by the Ministry of Health concludes that only 0.17% of all health visits to clinics and hospitals were related to genetic disorders.⁵⁵ This likely underestimates the burden of genetic diseases in the country.⁵⁶

Today hemoglobinopathies, glucose-6-phosphate dehydrogenase deficiency, and many metabolic disorders are common in the Middle East.⁵⁷ These are a small sample of the over seven-hundred genetic disorders that have been found in Arab populations throughout the world.⁵⁸ Despite emergent attempts to improve prevention programs and education targeting these diseases, their public health costs represent a significant challenge for Middle Eastern governments. For example, the cost of treating Niemann Pick and Gaucher diseases, two disorders found in Saudi Arabia that are caused by rare

⁵³ Ibid.

⁵⁴ Ibid.

⁵⁵ Ibid., 328.

⁵⁶ Ibid.

⁵⁷ Al-Gazali, Hamamy, and Al-Arrayad, "Genetic Disorders in the Arab World," 831.

⁵⁸ Tadmouri, "Genetic Disorders in Arab Populations," 20.

mutations, is \$30,000 per year for an infant.⁵⁹ This cost then increases proportionally with age, creating a burden few healthcare systems can shoulder.⁶⁰

In Jordan specifically, high maternal age, large family size, and traditionally high rates of consanguinity have contributed to a high prevalence of genetic diseases in the country, as well as the creation of new autosomal recessive conditions.⁶¹ It has been estimated that between 3.2 and 12 percent of males in Jordan may be affected by glucose-6-phosphate dehydrogenase deficiency, which can lead to hemolytic anemia, a type of anemia caused by the breakdown of red blood cells. Familial Mediterranean Fever, muscular dystrophy, cystic fibrosis, and many other genetic diseases are also present in the country.⁶² As with other countries in the region, a declining rate in morbidity and mortality attributed to infectious diseases and infant mortality means that the importance and expense of genetic diseases are growing in the kingdom.⁶³ One of the most challenging of these genetic diseases for the Jordanian government is beta-thalassemia.

Beta-thalassemia is distinguished from many other medical conditions in Jordan because of the government's legal obligation to pay for treatment for all citizens who have the disease. The tremendous cost of treatment as well as the high prevalence of carriers and those affected in the Jordanian population (the highest for any genetic disease in the country), has led to the disease taking on an especially prominent role in the public

⁵⁹ Al-Odaib et al., "A New Era," 1174.

⁶⁰ Ibid.

⁶¹ Hamamy et al., "Communities," 55.

⁶² Ibid.

⁶³ Ibid., 59.

health discourse. Specifically, it has motivated the design and implementation of a mandatory prevention program. In the following chapter I begin with an introduction to the disease, explaining thalassemia's molecular basis as well as its different variants. From there, I explain the burden of beta-thalassemia in Jordan, highlighting the government-borne cost of treatment and the hardships faced by those affected with the disease and their families.

Chapter Two - Thalassemia: Incidence, Cost, and Treatment in Jordan

What is Thalassemia?

Thalassemia is a family of inherited blood disorders caused by the production of abnormal hemoglobin. Its name derives from the Greek word “thalassa,” which means sea.⁶⁴ This is because it was first found among people living near the Mediterranean. Today, although still largely associated with the region, thanks to migration, thalassemia has been found in other places in the world, including all countries of the Middle East. Thalassemia is now recognized as the most common inherited single-gene disorder in the world.⁶⁵ There are approximately 240 million carriers worldwide and at least 200,000 affected individuals are born each year.⁶⁶

There are between 240 and 300 million molecules of hemoglobin in each red blood cell. Nearly ninety-five percent of these are of the alpha hemoglobin variety. Each of these alpha hemoglobin can be divided into two further subunits, called alpha and beta.⁶⁷ These are both necessary for the delivery of oxygen to red blood cells. The different types of thalassemia are initially classified according to which subunit they affect. I am focusing in this work on beta-thalassemia. Although alpha-thalassemia can also be a very debilitating condition, it has a very low frequency in Jordan and thus the prevention program focuses on the beta-version.

⁶⁴ CAGS, “Alpha Locus 1.”

⁶⁵ Tadmouri et al., “Blood Disorders,” 1.

⁶⁶ Cao et al., “Screening for Thalassemia,” 306.

⁶⁷ Tadmouri et al., “Blood Disorders,” 1

The severity of the beta-thalassemia disorder depends on the type of mutation. Only one gene, located on chromosome 11, controls the synthesis of the beta-chain. Two proper copies of the gene, one from each parent, are necessary for the correct production of the beta-chain. As opposed to alpha-thalassemia, most of the mutations in beta-thalassemia are point mutations in the DNA sequence.⁶⁸ There is a huge diversity of point mutations; for example, over fifty different mutations have been discovered among those with beta-thalassemia in Iran.⁶⁹

Individuals who are heterozygotes for a mutation, meaning that one of their genes is affected and the other is not, have a milder form of anemia called beta-thalassemia minor. Though they might not display any symptoms, these individuals are carriers; their status can almost always be identified by a combination of a CBC, or complete blood count test, and hemoglobin electrophoresis.⁷⁰ Those who are homozygous for mutations, meaning that they carry two copies of the same mutation, have beta-thalassemia major. This condition is also known as Cooley's anemia, named for Thomas Cooley, an American doctor who was the first to describe it in 1925.⁷¹ Beta-thalassemia major leads to a life-threatening anemia that must be treated with lifelong blood transfusions and iron chelation therapy to ensure survival past the second or third decade of life. Symptoms include fatigue, shortness of breath, bone malformations leading to facial deformities, jaundice, delayed puberty, and an enlarged spleen. Common complications include

⁶⁸ Strauss, "Genetic Counseling for Thalassemia," 366.

⁶⁹ Ibid.

⁷⁰ Ibid.

⁷¹ Ibid.

infections as well as heart and liver disease. This is the form of thalassemia targeted by the Jordanian premarital prevention program and the condition I focus on in this work. There is also a beta-thalassemia intermedia. This can occur in those individuals with two different mutations, as well as certain homozygous mutations.⁷² Clinically speaking, it is differentiated from thalassemia major by the number of blood transfusions required.

The inheritance pattern of beta-thalassemia follows basic Mendelian genetics. If both parents carry the trait, there is a one in four chance that, in each pregnancy, their child will inherit two abnormal genes, resulting in beta-thalassemia major.⁷³ This condition requires constant and expensive treatment.

The Burden of Beta-Thalassemia: Cost and Treatment

In Jordan, as mentioned above, the government is responsible for providing treatment for thalassemia to all citizens. There are four thalassemia centers: one in the capital Amman, two in the North in Irbid and Zarqa, and one in the center of the country in Karak. I visited the facilities at the Al-Bashir hospital in Amman.

The Al-Bashir hospital is one of the largest in the country and it features a dedicated thalassemia center that was founded in 1995. Before then, thalassemia was included under the pediatric department. The journey from my hotel to the hospital was long; the hospital is located in the Wehdat area of Amman, home to the aforementioned Palestinian refugee camp of the same name. My cab driver informed me that some

⁷² Ibid.

⁷³ Likewise, there is a fifty percent chance their child will be a carrier for the disorder and a twenty-five percent chance their child will be neither a carrier nor affected.

embassies tell their citizens not to visit the poor area. When I asked whether it was in fact so dangerous, he readily agreed.

The thalassemia center is located in one of the many buildings throughout the sprawling hospital campus. With no readily identifiable welcome desk, I just walked in to the area labeled the treatment center. A series of large rooms with beds split off of the main hallway on the left and on the right were the doctors' offices. I introduced myself to the doctors and they asked me to wait while they finished speaking with some patients. As I positioned myself in the hallway in one of the waiting chairs, a patient came to talk to me.

'Imad was a beta-thalassemia patient visiting the hospital because of pain in his kidney. This visit was in addition to his normal appointments for transfusions, which happen about every three weeks. He asked me about my research and was excited to learn that I had been in an IVF lab the day before. 'Imad was training to become a bioengineer himself and he was specializing in IVF. Once he had seen the doctor, 'Imad said good bye and walked out of the hospital; there was no sign-in procedure and no checkout. Since thalassemia treatment is provided free, there is apparently no need to deal with accounting measures.⁷⁴ This, along with the frequent visits these patients make to the hospital, seems to explain their general nonchalance. Most patients simply wandered around through the wide hallway, walking back and forth between the rooms with beds and the doctor's office. They appeared to be largely on their own, waiting for their transfusions.

⁷⁴ This seems to create a considerable opening for financial irregularities. Future research on healthcare in Jordan might wish to focus on the reported cost of treatment versus the amount of services provided.

Blood transfusions are part of the standard treatment for beta-thalassemia major. Lasting one to four hours and scheduled every two to four weeks, they can amount to as much as fifty-two pints of blood per year.⁷⁵ These temporarily provide patients with the necessary amount of healthy red blood cells. Blood transfusions are followed by chelation therapy to remove excess metals from the body and thus help address the iron overload.

Before the advent of an oral chelating agent, Exjade (or Deferasirox), patients needed to organize their lives around daily injections of Desferal (or Deferoxamine).⁷⁶ Desferal is administered either intravenously or more commonly in a painful subcutaneous injection process by a battery-operated pump. The injection is scheduled nightly, at least five times per week, and takes between eight and twelve hours. Oral alternatives, although certainly much easier to take, are more expensive and have side effects, thus requiring continual monitoring.⁷⁷ There are problems with compliance for both versions of the iron chelators and thus the average survival is only about thirty-two years, less than half of what would otherwise be possible.⁷⁸

As I waited, the center had the feeling of being at a standstill. Perhaps as a literal manifestation of this, the clock in the hallway was stopped. This was not the crowded, magazine-filled waiting room that one would expect in America. A cold draft came in through the open door I had walked in and the metallic chairs in the hallway were

⁷⁵ National Heart, Lung, and Blood Institute, "Thalassemia Treatment" and Cooley's Anemia Foundation, "About Thalassemia."

⁷⁶ Strauss, "Genetic Counseling for Thalassemia," 366.

⁷⁷ Ibid.

⁷⁸ Ibid., 367.

reminiscent of those at an airport terminal. As with airline passengers walking to the ticket counter, the patients simply approached the doctor's office one by one, returning to the beds after their demands were satisfied. Eventually it was my turn.

The first thing I noticed when I walked into the office was that there was no computer. Rather, piles of medical forms and paperwork were strewn around a large wooden desk. Two doctors were in the office, one on loan from the pediatrics department. I began to interview the doctor behind the desk. Although the nameplate read "Head of the Center," Maha was instead sitting there; the main doctor, a very senior official actively involved in thalassemia advocacy, had left the hospital for the day, despite it only being nine in the morning.

Maha was a Ministry of Health doctor assigned to work at Al-Bashir. She explained that although her background was in family medicine, thalassemia was considered an important part of this field in Jordan. Maha helps to treat around 675 patients at the center, of which between four and five hundred have beta-thalassemia. This is nearly forty percent of the number of beta-thalassemia patients in Jordan. Sometimes foreigners, such as people from Syria, come to the clinic. For as Maha explained, "our blood here is safe." Before the introduction of blood bank monitoring, contracting blood-borne diseases such as Hepatitis C was a common fear for patients.

In addition to providing blood treatments and iron chelation therapy, the doctors at Al-Bashir attempt to provide what Maha called the "social aspect" of care. For thalassemia patients, this includes psychological care to help them deal with depression. This is important, as studies have found a huge psychosocial burden on children and

adolescents with thalassemia.⁷⁹ Moreover, a charitable organization for patients with thalassemia associated with the hospital helps to secure them work at the Amman municipality. This is one part of the “economic aspect” of care; the doctors also provide notes to excuse patients from work for their blood transfusions.⁸⁰

Besides blood transfusions, bone marrow transplants have also shown promise as a form of therapy for beta-thalassemia. Bone marrow transplants involve the replacement of all the patient’s blood-producing cells in the marrow with those of a closely matched donor.⁸¹ These procedures, although potentially able to cure the disease, are limited by cost and risk, as well as by difficulties in locating suitable donors, usually siblings.⁸² The mortality rate for those receiving transplants from matched, though unrelated donors, has been estimated at twenty percent worldwide.⁸³ Many people who receive transplants face problems with infertility. Furthermore, even if the transplant itself is successful, the disease persists in a quarter of patients who receive the operation.⁸⁴

At the University of Jordan medical school, I spoke with a hematologist, Sami, who frequently performs bone marrow transplant operations in Jordan. As mentioned above, one of the main dilemmas for those who are seeking a bone marrow transplant is locating a donor. Sami explained why this is not an easy task: “Theoretically you have to

⁷⁹ Gharaibeh, Amarneh, and Zamzam, “The Psychological Burden,” 634.

⁸⁰ This combined socioeconomic aspect of care may represent an important opportunity for patients to use their diagnosis as a way to obtain social capital. Further research could focus on the interaction between patients with beta-thalassemia in Jordan and their diagnosis and how physicians and public health officials perceive them.

⁸¹ Miller, “Thalassemias.”

⁸² Strauss, “Genetic Counseling for Thalassemia,” 366.

⁸³ La Nasa et al., “Unrelated Bone Marrow Transplantation,” 186.

⁸⁴ Lucarelli et al., “Bone Marrow Transplantation,” 417.

have four kids before you can find another matching donor...this may mean you have the four of them beta-thalassemia majors and this is disaster for the family.” The upshot of this, Sami concluded, is that only approximately fifteen to eighteen percent of individuals in Jordan are potential candidates for the procedure. One advantage to consanguineous marriages is that one may find suitable donors in cousins, not necessarily siblings. Despite this, the number of patients who receive transplants in Jordan is small; Sami suggested that the total probably did not exceed twenty a year, of which he personally accounted for half. For these operations, Sami explained that there was a “reasonably good” success rate, with a mortality rate at around fifteen percent. For those who cannot be cured by the transplant surgery, the government must continue to provide treatment. This may create a situation in which government health officials might pressure patients to undergo transplant surgery to reduce future costs. I did not find any evidence of this practice in Jordan. However, it would be useful to explore the process by which patients and their families decide to pursue this risky, though potentially curative treatment, and what role doctors and other healthcare professionals may play.

In 2008, there were around 1,400 people recorded as being affected by beta-thalassemia in Jordan, as well as approximately over 200,00 carriers.⁸⁵ This estimate is based on studies which have found the carrier frequency for beta-thalassemia to range

⁸⁵ Al-Hait, “Barnamaj,” 10.

from three to six percent.⁸⁶ The cost of treating thalassemia patients in Jordan is estimated by the Jordan Thalassemia and Hemophilia Society to be over fourteen million dollars per year, much of it for the over 25,000 blood units they receive annually.⁸⁷ This is just a fraction of the amount that the government devotes every year to health spending.⁸⁸ However, if one takes the cost of treating fourteen hundred patients to be fourteen million dollars, that means the government spent over sixty times what it spent per capita in 2007 on healthcare to treat one patient with beta-thalassemia major.⁸⁹ Maha estimated the costs to be even higher.

It costs the Ministry of Health around eighty-five dollars to test and screen each unit of blood for transfusion.⁹⁰ Oral chelating therapies are given for those patients who are less than fifteen years old and those adults with medical allergies or unique social situations (she gave the example of a single, working mother). According to Maha, the cost of Exjade is almost 850 dollars for each twenty-eight tablet packet. Patients take between four and five 250 or 500 milligrams tablets per day. The dosage depends on weight and grows with age. She explained it is twenty to forty milligrams per kilogram of body weight. This means that the cost can easily reach more than 20,000 dollars per year

⁸⁶ Hamamy et al, "Communities," 55. Mourad, a molecular geneticist who I spoke with, was highly skeptical of these carrier estimates, explaining that the authors "never provide how they come up with this percentage." These studies are limited, according to Mourad, because of a lack of a true, comprehensive screening program for carriers in the country. In his opinion, between fifteen and twenty percent of the population is a carrier for at least one mutation for thalassemia. While the lack of a thorough carrier screening program may undermine the efficacy of the aforementioned estimates, one might expect a much higher birth rate of children with thalassemia if Mourad was correct in his assumptions.

⁸⁷ Malkawi, "A Race with Time."

⁸⁸ Jordanian Ministry of Health, *Annual Statistics Report*, 3.

⁸⁹ Ibid., 52.

⁹⁰ Hazaimah, "Fayez Defends 'blood fees.'"

for the oral tablets alone. Maha added that the injectables are not much cheaper, as each of the four daily injections costs around eleven dollars. Access to transfusion and chelation therapy means that most patients with beta-thalassemia live until their thirties and forties; Maha noted that there was even one patient at Al-Bashir who was forty-eight or forty-nine. The lifetime cost of treating that individual is seemingly tremendous. These high numbers from Jordan, however, appear to be in line with those of other countries.

According to the World Health Organization (WHO), the cost of treating 15,000 patients in Iran in 2000 was \$200 million, or about \$13,300 per person.⁹¹ An estimate in the United Kingdom in 1999 calculated the annual cost of treating thalassemia at around \$19,000 per year in the patient's preteen years, rising to \$128,000 later in life.⁹² Given the average life expectancy of those with the disease (thirty-two years), the overall lifetime cost was estimated in 1999 at \$320,000.⁹³ Some of these estimates, along with those put forward by Maha, are slightly higher than those presented by official sources. This may suggest that not all citizens with thalassemia are receiving proper treatment. Regardless, the current cost of treating thalassemia to the Jordanian government is clearly immense. This does not include other costs to the individual and family associated with the disease, economic and otherwise.

Consanguineous marriages are an important part of Jordanian society and a major contributor to the prevalence of autosomal recessive diseases in the country, including thalassemia. In the next chapter, I introduce the phenomenon of consanguineous marriage

⁹¹ Christianson, Streetly, Darr, "Lessons from Thalassemia Screening in Iran," 1160.

⁹² Strauss, "Genetic Counseling for Thalassemia," 367.

⁹³ Ibid.

as it is found throughout the Middle East, before moving into the specific Jordanian context. The traditional practice poses serious challenges for the public health sector. In the eyes of the medical profession, while they appear to have some social benefits, consanguineous marriages also have a clear health cost.

Chapter Three - Consanguinity in Jordan: A Challenging Tradition

An Introduction to Consanguineous Marriage in the Middle East

Consanguineous marriages are typically defined as marriages between people who are second cousins or closer.⁹⁴ They are customary in the Middle East and parts of South Asia, as well as in some Jewish communities and other groups in sub-Saharan Africa and South East Asia.⁹⁵ It is estimated that one in five people in the world live in places where there is an established preference for consanguineous marriage.⁹⁶ Nearly ten percent of children are estimated to have consanguineous parents.⁹⁷ Even among North Americans and Western Europeans, many of whom live in countries where consanguineous marriage is prohibited by religious tradition or law, 0.5 percent of the population is reported to marry their own cousins.⁹⁸

Despite consanguinity's widespread nature and the fact that it predates Islam, the practice is often associated with the religion.⁹⁹ However, the Qur'an is clearly neutral toward consanguineous marriage; some scholars go further and even suggest that it discourages the practice.¹⁰⁰ The Qur'an explicitly forbids uncle-niece and aunt-nephew

⁹⁴ Modell and Darr, "Genetic Counselling," 225.

⁹⁵ Ibid.

⁹⁶ Ibid.

⁹⁷ Ibid.

⁹⁸ Inhorn et al., "Male Infertility and Consanguinity in Lebanon," 181.

⁹⁹ Bittles and Hamamy, "Endogamy and Consanguineous Marriages," 89.

¹⁰⁰ Strauss, "Genetic Counseling for Thalassemia," 368 and Teebi, "Introduction," 4.

marriages.¹⁰¹ These later marriages are thought to be nonexistent in the region.¹⁰² A number of sayings attributed to the Prophet, including some repeated by my informants, encourage marriages between non-relatives.¹⁰³ As Fatima, a professor of nursing at the Jordanian University of Science and Technology, explained to me: “In Islam, the Prophet Muhammad advised to have faraway marriages, not to have kin marriages.”

Nevertheless, consanguineous marriages are still extremely prevalent in the Middle East, ranging from 16.5 to 78 percent in different regions.¹⁰⁴ The rates vary widely within and between countries: 36.4 percent in Algeria; 32 percent in Bahrain, 29 to 39 percent in Egypt, 23 to 78 percent in Iran, 51.3 percent in Jordan, 35 to 54.3 percent in Kuwait, 29.6 percent for Lebanese Muslims and 16.5 percent for Lebanese Christians, 46.5 percent in Libya, 60.1 percent in Mauritania, 54 percent in Oman, 46 percent in Qatar, 54 to 57 percent in Saudi Arabia, 65 percent in Sudan, 38 percent in Syria, 40.2 percent in Tunisia, 21.2 percent in Turkey, and 50 to 54 percent in the United Arab Emirates.¹⁰⁵ There is a unique preference in the Middle East for patrilateral parallel first-cousin marriages, that is, marrying the father’s brother’s daughter.¹⁰⁶ In more traditional Arab societies, such as Jordan, a man has the common law right to marry his first cousin; if she chooses to marry someone else, he may be entitled to financial compensation.¹⁰⁷ If

¹⁰¹ Qur’an 4:23.

¹⁰² Teebi, “Introduction,” 4.

¹⁰³ Bittles and Hamamy, “Endogamy and Consanguineous Marriages,” 89.

¹⁰⁴ Inhorn et al., “Male Infertility and Consanguinity in Lebanon,” 181.

¹⁰⁵ *Ibid.*, 167.

¹⁰⁶ *Ibid.*, 181.

¹⁰⁷ Bittles and Hamamy, “Endogamy and Consanguineous Marriages,” 89.

two first-cousins marry, this means that the couple has at least one, if not two, sets of grandparents in common.¹⁰⁸ The highest first-cousin marriage rates have been recorded in Jordan (32 percent), Oman (34 percent), Saudi Arabia (31.4 to 41.4 percent), the United Arab Emirates (30 percent), and Yemen (32 percent).¹⁰⁹

There does not appear to be any consistent movement in these rates. For example, while first-cousin marriages have become more common in some countries (Yemen, United Arab Emirates), they have either stayed stable (Oman) or declined (Jordan, Lebanon, Kuwait, Syria) in other places in recent years.¹¹⁰ This is despite a clear increase in the standard of living and level of education in the region, factors predicted by some to lower the rate of consanguinity. In 1963, one American sociologist, William Goode, proposed a theory of modernization. It posits changes in family structure and relationships; these are supposed to result in the decline of consanguineous marriages. Goode suggests that as people begin to enjoy greater freedom, they will be more likely to choose mates that are not their close relatives.¹¹¹ First to do so will be those who are of higher social status, who will desire more freedom.¹¹² Reports from the Middle East complicate this narrative.

In 1996, medical anthropologist Marcia Inhorn conducted a study on consanguinity in Egypt. She discovered that poorly educated, nonworking women tended to have consanguineous marriages, a result consistent with other findings from the

¹⁰⁸ Inhorn et al., "Male Infertility and Consanguinity in Lebanon," 181.

¹⁰⁹ Ibid., 168

¹¹⁰ Ibid.

¹¹¹ Givens and Hirschman, "Modernization and Consanguineous Marriages in Iran, 182.

¹¹² Ibid.

region.¹¹³ Among men, however, it has been found that those who have a higher educational and occupational status are more likely to marry other family members.¹¹⁴ Some have suggested that these males, seen as “valuable assets,” are pressured to stay within the family.¹¹⁵ This is just one of the social benefits at the core of the prevalence of consanguineous marriage and the reason that the practice has persisted in the Middle East and throughout the world.

There are many reasons to pursue a consanguineous marriage. First, these marriages serve to strengthen familial and tribal ties. There is also a reduced level of uncertainty around these marriages, about both one’s spouse as well as their family.¹¹⁶ A common saying in the Middle East is ‘a spouse that you know is better than the one you don’t know, and a cousin takes better care of you.’¹¹⁷ This may be true given the increased stability of consanguineous marriages compared to those between unrelated partners.¹¹⁸ In marrying outside the family, women face greater uncertainty. Consanguineous marriages provide them with better relationships with their in-laws and the opportunity for reduced bride wealth payments.¹¹⁹ Thus, consanguineous marriages

¹¹³ Inhorn et al., “Male Infertility and Consanguinity in Lebanon,” 182.

¹¹⁴ Ibid., 182.

¹¹⁵ Ibid.

¹¹⁶ Modell and Darr, “Genetic Counselling,” 226.

¹¹⁷ Teebi, “Introduction,” 4.

¹¹⁸ Modell and Darr, “Genetic Counselling,” 225.

¹¹⁹ Inhorn et al., “Male Infertility and Consanguinity in Lebanon,” 181.

are often cited as beneficial towards women.¹²⁰ This may partially explain the higher proportion of poorly educated and nonworking women in consanguineous marriages.¹²¹

By marrying within the family, partners also help to preserve property and wealth. This is especially useful for rich families and tribes.¹²² In addition to maintaining financial wealth, consanguineous marriages serve to secure the family's strength and identity.¹²³ There is a strong belief in the Middle East that one's personal identity is defined by his or her family.¹²⁴ As Inhorn and others explain, inner-family marriage is seen by some as the only way to assure the family's strength and thus the individual member's security.¹²⁵ In strengthening their family ties and personal identities, however, individuals who engage in consanguineous marriages also risk weakening their offspring.

Consanguinity has been linked to a variety of health problems: increased morbidity and mortality, genetic disorders, congenital malformations, learning difficulties, blindness, hearing problems, and some metabolic disorders.¹²⁶ This is because of the increased homozygosity in offspring from inbreeding.¹²⁷ As geneticists Alan Bittles and James Neel explain, all of us are thought to be heterozygous carriers for multiple rare recessive genes which, if made homozygous, would lead to a wide range of

¹²⁰ Modell and Darr, "Genetic Counselling," 225.

¹²¹ Inhorn et al., "Male Infertility and Consanguinity in Lebanon," 181.

¹²² Teebi, "Introduction," 4.

¹²³ Inhorn et al., "Male Infertility and Consanguinity in Lebanon," 181.

¹²⁴ Ibid.

¹²⁵ Ibid.

¹²⁶ Modell and Darr, "Genetic Counselling," 227.

¹²⁷ Bittles and Neel, "The Costs of Human Inbreeding," 117.

handicaps and disorders.¹²⁸ Consanguineous marriages increase the probability that both partners will carry the same specific rare gene (inherited from a common ancestor) and thus that their child will be homozygous for it.¹²⁹ It is possible to calculate the exact probability of homozygosity for any type of consanguineous marriage. This inbreeding coefficient is 0.0625 for first-cousin marriage and 0.0156 for second-cousin marriages. That is, there is an additional 1/16 and 1/32 of variation in the DNA respectively that is rendered homozygous.¹³⁰ This increased homozygosity is not always harmful.

Most recessive traits are harmless, meaning that a higher proportion of consanguineous marriages may manifest itself in a community where blue eyes are more common.¹³¹ At the same time, it can also contribute to the spread of otherwise rare recessive diseases for it is unlikely that a person would marry another carrier unless they are related.¹³² Given the fact that when parents are in a consanguineous marriage their children are more likely to enter a similar marriage, it is not surprising that so many different genetic disorders are found in the Middle East.¹³³ Even for less rare diseases, such as beta-thalassemia, consanguinity increases the chance of having an affected offspring. In countries where there is a long tradition of inbreeding, the risk is even higher.

¹²⁸ Ibid.

¹²⁹ Ibid.

¹³⁰ Ibid.

¹³¹ Modell and Darr, "Genetic Counselling," 225.

¹³² Ibid., 227.

¹³³ Hamamy et al., "Consanguineous," 514.

Fears of consanguinity, however, are overplayed. In countries such as the United States where the populations are so outbred, there is very little risk of physical or mental handicaps due to consanguineous marriage.¹³⁴ Nevertheless, first-cousin marriage is banned in twenty-four American states; the United States is the only country in the West with cousin marriage restrictions.¹³⁵ This appears to be the legacy of an earlier cultural bias against kin marriage and the eugenics movement.¹³⁶ In discussing the role of consanguinity in other societies, such as in Jordan, it is important to be aware of these tendencies.

Consanguinity in Jordan

There is a strong tradition of consanguinity in Jordan. Although rates appear to have been declining, they still remain high. A study conducted on about two-thousand marriages from between 1969 and 1999 found a rate of thirty-two percent for first-cousin marriages.¹³⁷ This was part of an overall 51.25 percent consanguinity rate for marriages in the country.¹³⁸ In other regions of the country, rates have been reported to be as high as sixty percent.¹³⁹

¹³⁴ Strauss, "Genetic Counseling for Thalassemia," 368.

¹³⁵ Ottenheimer, *Forbidden Relatives*, 96.

¹³⁶ Ibid., 118 and Modell and Darr, "Genetic Counselling," 226.

¹³⁷ Khoury and Massad, "Consanguineous Marriage in Jordan," 772.

¹³⁸ Ibid.

¹³⁹ Dasouki and El-Shanti. "Genetic Disorders in Jordan," 327.

In a 2007 survey sponsored by USAID, forty percent of women aged 15-49 reported that they were related to their current husband.¹⁴⁰ As one might expect, these marriages are more common among rural (forty-nine percent) than urban women (thirty-eight percent), though not dramatically so.¹⁴¹ Similarly, while thirty-one percent of women with higher than a secondary education had a husband they were related to, this was true for forty-seven percent of women with no education.¹⁴² Age at marriage and the woman's socioeconomic status were both inversely related to consanguinity.¹⁴³ In an effort to provide a deeper, qualitative insight into these statistics I asked various medical and health officials about consanguineous marriages in Jordan.

The individuals who I spoke with about consanguinity were located in the capital city of Amman and the third largest city, Irbid. Educated, wealthy, and employed in a profession that is seemingly inherently averse to consanguineous marriages, it is unsurprising that my informants were almost universally dismissive of the practice.¹⁴⁴

According to Marwan, the Oxford-trained microbiologist, consanguineous marriages are becoming less popular: "It's on the decline, definitely it's on the decline. Because of social changes in Jordan. It will disappear sooner than later I think. Because the rate of social change is quite fast these days. And a lot of these marriage related habits are changing." I asked Marwan whether he saw this as a good thing: "Of course it is,

¹⁴⁰ Department of Statistics [Jordan] and ICF Macro, *Jordan Population and Family Health Survey 2007*, 66.

¹⁴¹ *Ibid.*, 67.

¹⁴² *Ibid.*

¹⁴³ *Ibid.*, 67.

¹⁴⁴ This is confirmed by the lower rate of consanguinity in Amman when compared to other regions in the country (Bittles and Hamamy, "Endogamy and Consanguineous Marriages," 87).

because having more options. You Americans are telling the whole world that, that the option is a good thing.” When pressed to identify possible benefits to these marriages, he had difficulty in coming up with any: “They’ll stick to each other even if they hate each other...sometimes you see these marriages going on despite all the misery, is that a benefit? I don’t think so.” The often-touted economic advantage was not something that Marwan saw as a major factor in these marriages:

It’s not the benefit, most of those consanguineous marriages are within families and tribes down...the social ladder. They are not royals keeping their blood within the family. It’s the tradition. It’s the tradition. It’s my cousin is more like me. He understands where I come from, my background. So we fit each other better. We don’t have to adapt to a new way of life. It’s that more than the benefit.¹⁴⁵

Ahmad, an immunologist at the National Center for Diabetes, Endocrinology, and Genetics, expressed similar sentiments. When I asked him if it was a positive thing that the marriages appeared to be decreasing he responded affirmatively: “Of course...because we have a lot of intra-family disease in the whole country. Familial diseases is very, very common in Jordan.” Sami, the hematologist at the University of Jordan Medical School, proved equally dismissive of the tradition. Citing Islam’s opposition to the practice, Sami was unsurprised that, in his mind at least, it was slowly fading in the country:

It’s disappearing because it’s not based on the religious background. This is in a way, it’s anti-religion. But I think it’s made by necessity, convenience, and short-cuts, cause of villages at the time it was very difficult to travel and go around and to know more people.

¹⁴⁵ This is an interesting statement by Marwan as it casts a better fit between couples as a non-benefit. Perhaps this references a conception of marriage based on economics, rather than other, more abstract factors. Future research should focus on conceptions of marriage in Jordan and the Middle East as a whole with an eye to how they may affect public health initiatives.

But now, you know with the openness, with the education, university, and work and people mix.

According to Sami, there is no cost to this tradition falling by the wayside. When I asked whether he thought that even some tribes may be affected by the disappearance of this practice, he expressed doubts: “It’s no longer important, on the contrary...I can see it from the people’s standard attitude now. Consanguineous marriages are very very much being reduced to almost will disappear soon. I’m not saying it as something which people would try to keep it, no on the contrary.” One of the lab technicians I spoke to at the Jordanian University for Science and Technology, Mustafa, was a young man, still unmarried. He explained that consanguineous marriages have the clear advantage in Jordan of being much cheaper than other marriages.

According to Mustafa, the cost of marriages in Jordan is very high, ranging from 12,000 to 20,000 dinars, with a minimum of 10,000 dinars. That is almost three times the average per capita income in the country.¹⁴⁶ Families, understanding the financial burden marriage poses, may request less money. This helps men to avoid the situation in which they have to work many years to pay for the marriage, while the women sometimes choose not to wait; the men are forced afterwards to pursue a traditional, arranged marriage. These appear to be a popular option. One study in Jordan of marriages from 1969 to 1979 found that eighty percent of marriages were arranged.¹⁴⁷ Similarly to Mustafa, Mourad, a molecular geneticist, appeared to have a more nuanced understanding of the role of consanguinity in Jordanian society.

¹⁴⁶ Central Intelligence Agency, “The World Factbook.”

¹⁴⁷ Khoury and Massad, “Consanguineous Marriage in Jordan,” 774.

When I first asked Mourad whether he saw any potential negatives to a reduction in the consanguinity rate in Jordan, he was clear: “Absolutely not. I believe everything will be positive when you reduce consanguineous marriages.” In Mourad’s mind, lowering consanguinity is key to preventing the spread of genetic diseases in Jordan. At the same time, he recognized “a lot of people in the public” would disagree with his negative views on the practice.

Despite the near unanimity of the above opinions it is important to remember their origin: the educated medical and scientific urban elite. In this social stratum, consanguineous marriages have traditionally had a weak foothold. The aforementioned studies on the rates of these marriages in Jordan confirm as much. I was unable to travel to the rural areas of Jordan during my time in the country. However, recent reports from the country suggest that, despite the overall decline of the tradition in Jordan, these marriages remain popular outside of the cities.¹⁴⁸ In the following chapter I will discuss the prevention program for beta-thalassemia in Jordan, focusing on questions of abortion, genetic counseling, and ways to evaluate the program. When considering the incidence of beta-thalassemia in the country, as well as the possible impact the prevention program may have on consanguinity, it is important not to forget these other populations.

¹⁴⁸ Department of Statistics[Jordan] and ICF Macro, *Jordan Population and Family Health Survey 2007*, 67.

Chapter Four - Reinventing the Wheel? The Prevention Program for Beta-thalassemia in Jordan

In 2002, the Jordanian government passed a new public health law number 54. In its first chapter, it outlines the responsibilities of the Ministry of Health, including monitoring the population and providing preventative and curative services.¹⁴⁹ In addition to being instructed to “encourage breast feeding” and “provide free maternal and child health care,” the Ministry of Health is required to enforce a law that subjects those who are planning to marry to a premarital blood test for genetic diseases.¹⁵⁰ This chapter examines the Ministry of Health’s implementation of the program, which started in 2004, paying particular attention to two important, open questions surrounding the program: the legality of abortion and the quality of genetic counseling. I conclude by stepping back from the program in an attempt to evaluate its current progress and future prospects.

The Premarital Testing Program

The premarital testing program in Jordan has gone through multiple iterations. It first began as a voluntary test. This original initiative was motivated by the activities of the Jordanian Association for Friends of Blood Diseases.¹⁵¹ The organization hosted various lectures and seminars throughout the kingdom to raise awareness about thalassemia, resulting in the formation of a national committee for premarital testing and

¹⁴⁹ Halasa, “Mapping Healthcare Financing,” 78.

¹⁵⁰ Ibid.

¹⁵¹ Al-Hait, “Barnamaj,” 11.

the institution of the voluntary test.¹⁵² From June 1996 to June 2004, three thousand individuals were screened for thalassemia and sickle cell anemia.¹⁵³ The results were not encouraging: three percent were found to be carriers for thalassemia (and 0.8 percent for sickle cell anemia).¹⁵⁴ In a 2009 booklet published on the prevention program, doctors from the Ministry of Health point to these results as the trigger for the Ministry's interest in thalassemia and recognition of thalassemia as one of the most common diseases in the kingdom.¹⁵⁵ Despite this progress, the initial program was filled with drawbacks.

Officials at the Ministry of Health have identified a number of problems with the voluntary initiative: laboratories conducted the wrong tests (i.e. assessing liver function instead of blood cell count), couples split unnecessarily (i.e. when only one person was a carrier), people failed to understand the tests (some thought they were fertility tests), and there was a serious deficiency in the availability of appropriately trained laboratory technicians and genetic counselors.¹⁵⁶ Furthermore, the three thousand individuals tested represented only 2.2 percent of the marriages conducted in those eight years.¹⁵⁷ The program was clearly not going to make significant inroads. In an attempt to improve upon these deficiencies and take meaningful action against thalassemia, the government instituted the mandatory program in 2004.

¹⁵² Ibid.

¹⁵³ Ibid.

¹⁵⁴ Ibid.

¹⁵⁵ Ibid., 12.

¹⁵⁶ Ibid., 12.

¹⁵⁷ Ibid., 11.

This initiative, the first preventive program for genetic diseases in Jordan, is seen as an improvement upon its predecessor in a number of ways: it includes a better awareness campaign, allows for the use of private laboratories as well as government ones, and sets out specific protocols for testing for thalassemia.¹⁵⁸ This testing, however, is not done at any centralized location. Couples who are intending to marry may have their blood taken at either a Ministry of Health center, where it is provided for free, or at a private laboratory. The one private laboratory that I visited charged fifteen dinars for a test, roughly the equivalent of twenty dollars; this is not a prohibitive amount for anyone in the lower-middle class or up. The laboratories first perform a CBC. At the Ministry of Health's comprehensive health clinic in Amman, there is a turn around period of about one day for the results. If the Mean Corpuscular Volume, or MCV, level is less than eighty, then the individual is asked to do further testing, specifically hemoglobin electrophoresis. This is a more conclusive test and can help to separate cases of mild anemia from more serious conditions.

The hemoglobin electrophoresis test measures the different kinds of hemoglobin in the patient's blood. At this point, a diagnosis of carrier status for beta-thalassemia can be made, as well as alpha-thalassemia and sickle cell anemia. A hemoglobin A2 level above 3.5 percent suggests the presence of the beta-thalassemia trait; however some carriers may have normal hemoglobin A2 levels.¹⁵⁹ Thus if doubts persist, couples can pursue further testing, attempting diagnosis at the molecular level. This is the first step that necessarily comes with a price tag, between fifty and ninety dinars. Most people,

¹⁵⁸ Ibid., 13.

¹⁵⁹ Cao et al., "Screening for Thalassemia," 311.

perhaps because of the cost, do not ask for this additional confirmation. Furthermore, the government will identify individuals as carriers based only on the CBC and hemoglobin electrophoresis test.

If both individuals are identified as carriers for beta-thalassemia, they are required to attend genetic counseling if they wish to pursue their marriage. There are seven official counseling centers, four of which are thalassemia centers within larger hospitals.¹⁶⁰ These are supposed to provide nondirective, educational counseling. If, after meeting with genetic counselors, a couple still wishes to marry, they must sign a paper affirming that they have received counseling and they will then be allowed to do so. Preliminary statistics suggest that forty percent of carrier couples in Jordan decide not to get married.¹⁶¹ For those who do continue, a file is opened at the Ministry of Health which keeps track of their pregnancies. During each of their pregnancies, the couple is offered the option to pay for prenatal genetic testing to determine whether their child is affected with beta-thalassemia. Due to its cost, this is not a choice that many Jordanians can afford to make. This also applies to assisted reproductive technologies such as preimplantation genetic diagnosis, or PGD, and IVF. While a combination of these two can be used to prevent having affected offspring, these are not practically available in the country.

Those couples not identified as both being carriers are allowed to marry with no further steps. The report from the laboratory is sent to the Ministry of Health and to the court where the presiding official approves their marriage. All that is asked of this official is that he notes the presence of the blood test and/or completion of counseling.

¹⁶⁰ Al-Hait, "Barnamaj," 19.

¹⁶¹ Ibid., 20.

I spoke with one hematologist at the University of Jordan Medical School, Sami, who suggested that he was among the first to come up with the idea for Jordan. Recognizing that there was a problem of beta-thalassemia in Jordan, he met with various officials at the Ministry of Health, attempting to push for a comprehensive approach to prevent the disease. The program in Jordan shares many characteristics with those found in other countries in the region including Bahrain, Cyprus, the Gaza Strip, Iran, the United Arab Emirates, Saudi Arabia, Tunisia, and Qatar. Iran's often-lauded program likely served as a model.¹⁶²

A mandatory screening program for beta-thalassemia was implemented in Iran in 1997. In this process, designated laboratories test couples who are sent to them from the marriage registrars.¹⁶³ There, similar to the Jordanian program, they perform a CBC and then, if necessary, hemoglobin electrophoresis. Unlike in Jordan, the man is tested first in Iran; the woman is only tested if the CBC shows the man's MCV to be below 80. This is to prevent some of the possible stigma for the woman. If both are found to have a hemoglobin A2 level of above 3.5 percent, they are referred to counseling. The government covers the planning, education, counseling, and surveillance of the program, but couples pay around five dollars for the screening test.¹⁶⁴ Counseling is provided by teams made up of a doctor and another person with a BSc degree in health studies and the consultations follow the WHO's ethical standards.¹⁶⁵

¹⁶² This is the case for many of the progressive healthcare policies adopted by the Islamic Republic. The success of health interventions in this religiously dominated country raises important questions for the pervasive narrative associating secularism with new medical technologies.

¹⁶³ Samavat and Modell, "Iranian National Thalassaemia Screening Programme," 1135.

¹⁶⁴ *Ibid.*, 1136.

¹⁶⁵ *Ibid.*, 1134-5.

When the program was first initiated, couples were not given the option of prenatal diagnosis and selective termination of pregnancy. An audit in 1999 showed that couples were still opting to marry instead of separating and that there was a demand for prenatal diagnosis and abortion.¹⁶⁶ Thus, it was proposed that the law be amended to allow the termination of pregnancy for fetuses affected by beta-thalassemia.¹⁶⁷ The decision to allow abortion involved a series of debates and bioethical discussions with both physicians and religious officials.¹⁶⁸ Finally in 2005, selective abortion for beta-thalassemia before sixteen weeks was approved despite worries by some that this would increase promiscuity.¹⁶⁹ The final legislation also includes about fifty additional medical conditions that, with the authorization of three medical authorities, can be grounds for an abortion.¹⁷⁰ The passing of this law has resulted in a surge in the number of couples pursuing prenatal testing.¹⁷¹ I should clarify that there is an important religious difference that allowed for this centralized decision to legalize abortion in Iran. Shi'ite Islam is formally organized under central clerical authorities. These clerics have the power to mandate changes to religious practice amongst believers. This is not the case with Sunni Islam (the predominant variant in Jordan) where religious authority is more diffuse.

¹⁶⁶ Christianson, Streetly, and Darr, "Lessons from Thalassemia Screening in Iran," 1116.

¹⁶⁷ Ibid.

¹⁶⁸ Strauss, "Genetic Counseling for Thalassemia," 370.

¹⁶⁹ Ibid., 371. As Strauss notes, there is considerable confusion about when abortion was finally allowed, but 2005 appears to be the date of the final ratification (Ibid.).

¹⁷⁰ Ibid.

¹⁷¹ Ibid., I should note that the cost of prenatal diagnosis in Iran is paid for by private and public insurance companies (Samavat and Modell, "Iranian National Thalassaemia Screening Programme," 1136).

About half of those who receive counseling in Iran go on to marry.¹⁷² More than ninety-eight percent of those couples who are found to have affected fetuses through prenatal testing choose abortion.¹⁷³ The result of the combination of prenatal diagnosis and abortion has been an overall reduction of the number of infants affected with thalassemia by seventy percent.¹⁷⁴ This success has led many to praise the Iranian example and wonder what lessons it offers other countries.¹⁷⁵ The case of Cyprus can be seen as another benchmark for success in beta-thalassemia prevention.

When the program began in Cyprus in 1973, the prevalence of the beta-thalassemia trait was estimated to be at sixteen percent, around five times the estimated rate in Jordan.¹⁷⁶ The cost of chelating therapy alone amounted to six percent of the Ministry of Health's budget in 1979.¹⁷⁷ This expense, as well as the limited availability of Deferasirox and blood, meant that it was doubtful the country could adequately support more affected individuals.¹⁷⁸ Given the aforementioned carrier rate and the country's population, the number of new cases of beta-thalassemia major was predicted to be seventy-one for 1978 and seventy-seven for 1979.¹⁷⁹ In those years combined, thanks to the active prevention program, only forty-one new cases were documented.¹⁸⁰ Today the

¹⁷² Ibid., 1135.

¹⁷³ Saniei et al., "Prenatal Screening and Counseling in Iran," 271.

¹⁷⁴ Christianson, Streetly, and Darr, "Lessons from Thalassemia Screening in Iran," 1115.

¹⁷⁵ See the articles by Christianson, Streetly, and Darr, as well as Strauss for two such examples.

¹⁷⁶ Angastiniotis and Hadjiminias, "Prevention of Thalassemia in Cyprus," 369.

¹⁷⁷ Ibid.

¹⁷⁸ Angastiniotis, Kyriakidou, and Hadjiminias. "How Thalassemia Was Controlled in Cyprus," 292.

¹⁷⁹ Angastiniotis and Hadjiminias, "Prevention of Thalassemia in Cyprus," 369.

¹⁸⁰ Ibid.

incidence of new beta-thalassemia births is close to zero.¹⁸¹ Between 1985 and 2007, the annual birth rate of homozygotes for beta-thalassemia major was between zero and two percent of the expected rate.¹⁸² One of the main factors in the success of the program has been the cooperation of the church.¹⁸³ The Orthodox Christian church in Cyprus will only bless the engagement or marriage of those who have been tested and advised, essentially making the test mandatory.¹⁸⁴ Furthermore, the series of diagnostic tests conducted by private laboratories are checked against tests at government clinics to guarantee accuracy.¹⁸⁵ These are not the only reasons for the program's success.

Writing in an often-cited paper from 1981, Cypriot thalassemia doctors Angastiniotis and Hadjiminias attribute a large part of the success of the program to free prenatal diagnosis and the availability of abortion; this is in addition to a successful education campaign and effective counseling.¹⁸⁶ The impact of the counseling can be seen in the cases of fourteen couples who between April 1978 and November 1979 requested termination of their pregnancy even without prenatal diagnosis.¹⁸⁷ More recently, American molecular geneticist Bernard S. Strauss explains that nearly one-hundred percent of couples who attend genetic counseling sessions in Cyprus pursue

¹⁸¹ Strauss, "Genetic Counseling for Thalassemia," 367.

¹⁸² Angastiniotis and Modell, "Global Epidemiology," 257.

¹⁸³ Angastiniotis, Kyriakidou, and Hadjiminias, "How Thalassemia Was Controlled in Cyprus," 292.

¹⁸⁴ Ibid.

¹⁸⁵ Angastiniotis et al., "Prevention and Control of Haemoglobinopathies," 379.

¹⁸⁶ Angastiniotis and Hadjiminias, "Prevention of Thalassemia in Cyprus," 370.

¹⁸⁷ Ibid.

prenatal testing and the implicit option of abortion.¹⁸⁸ The availability of pregnancy termination is clearly a large factor in the success of the programs in Cyprus and Iran in reducing the number of new beta-thalassemia cases. Similarly, ambiguities surrounding the role of abortion in Jordan have created difficulties for the Jordanian initiative.

Abortion in Jordan: An Open Issue

Nearly all of my informants in Jordan provided a different answer when I asked them about the legal status of abortion in Jordan. Bassem, an official at the Ministry of Health, explained that when he counseled couples, he emphasized “how it is okay to do abortion” in Jordan. At the same time, he recognized that there is “no obvious law” permitting abortion in the country. Bassem concluded, however, “we have an exit for them.” The law is not so clear on this.

According to the 1960 Jordanian Penal Code, any person who performs an abortion is subject to one to three years’ time in jail; this is to be increased by one-third if he or she is a medical professional.¹⁸⁹ A woman who induces her own miscarriage or allows for an abortion can be sentenced to between six months and three years in prison.¹⁹⁰ These penalties increase to include hard labor if the woman dies or if she does not originally provide consent.¹⁹¹ The Public Health Law number 21 of 1971 and the more recent Law number 54 of 2002 make an allowance for the termination of

¹⁸⁸ Strauss, “Genetic Counseling for Thalassemia,” 367.

¹⁸⁹ UN Population Division, Department of Economic and Social Affairs, *Abortion Policies*, 82.

¹⁹⁰ *Ibid.*

¹⁹¹ Jordanian Parliament, *Public Health Law no. 21*.

pregnancies that put the woman's life and health at risk.¹⁹² Two experienced and licensed doctors must approve the procedure, signing a document that verifies the abortion is necessary to protect the mother.¹⁹³ The operation has to be carried out in a general or maternity hospital and the woman must, if possible, provide written consent; otherwise, her spouse or whoever is legally responsible must provide it.¹⁹⁴ Between 1995 and 2000, there were nearly two-hundred thousand abortions carried out in Jordan.¹⁹⁵

This aforementioned allowance has been exploited by some women who, through prenatal diagnosis, find that they are carrying a child affected with beta-thalassemia. Sami explained that a woman can find two doctors, usually at private clinics, who will sign a document that says the pregnancy poses a threat to her health so she can then semi-legally go ahead with an abortion. This is despite the fact that a fetus affected with the disease poses no risk to the mother. Women are not forced to pursue these extralegal routes because of any consensus banning of abortion within Islam. In 1990, the Islamic Jurisprudence Council of the World Islamic League in Mecca issued a *fatwa* allowing for the select termination of pregnancies. The *fatwa* declares that an abortion may take place if a committee of physicians has determined that the fetus is severely malformed and its birth would have a seriously negative effect on itself and its family.¹⁹⁶ Furthermore, the

¹⁹² UN Population Division, Department of Economic and Social Affairs, *Abortion Policies*, 82 and Jordanian Parliament, *Public Health Law no. 54*, Section 2.

¹⁹³ *Ibid.*

¹⁹⁴ *Ibid.* I should mention that I was also informed in Jordan that abortion was allowed for fetal anencephaly, a malformation not compatible with life. A United Nations report from 2007 on global abortion policies also suggests that abortion is allowed in Jordan for fetal impairment (UN Population Division, Department of Economic and Social Affairs, *World Abortion Policies 2007*). I was not able to find any mention of this in the law.

¹⁹⁵ Hessini, "Abortion and Islam," 76.

¹⁹⁶ Al-Aqeel, "The Challenges," 39.

abortion for this untreatable and unmanageable malformation must be carried out before the one hundred and twentieth day after conception.¹⁹⁷ Ahmad stated that in multiple meetings with the Islamic and Christian clergies in Jordan they expressed no qualms about abortion for fetuses affected with beta-thalassemia. There is certainly a diversity of opinion within the Muslim legal community; for example, Iran allows abortion for fetuses affected with beta-thalassemia while Saudi Arabia does not.¹⁹⁸ Ahmad himself attributed Jordan's stance on abortion to a view based on the definition of life found in civil, rather than religious law.

For Sami, abortion is an "open issue" in Jordan. With the documented success of bone marrow transplants, despite the risks of these operations, it is now no longer true that thalassemia is incurable. Personally, while he used to take "a liberal approach" towards abortion with thalassemia, bone marrow transplants have made him more conservative. Speaking generally, Sami concluded that even without the lack of "legal authorization" for abortion for children affected with thalassemia in Jordan, "practically it is being done."

Despite its practical existence, the illegality of abortion for fetuses with beta-thalassemia creates a fundamental tension in the premarital testing program. While couples are provided with the opportunity to receive prenatal diagnosis, they are limited in their ability to legally act on this decision. Hamamy et al. explain that genetic counselors in Jordan currently "satisfy themselves" by declaring that they are making all

¹⁹⁷ Ibid.

¹⁹⁸ Strauss, "Genetic Counseling for Thalassemia," 370.

options available to the couple.¹⁹⁹ Given the lack of transparency surrounding abortion in Jordan, it is unclear whether this is necessarily a positive.

Sami offered that abortion, such as it is practiced in Iran and Cyprus, was not a suitable method for preventing the disease in Jordan, presumably because of traditional cultural attitudes: “In our setting...abortion is not something taken easily, therefore most of the preventive steps have to take a non-abortion approach.” Thus, citing the aforementioned examples, he supported a premarital test to detect carriers without the option of termination. It was in the early 2000s that Sami began meeting with the Ministry of Health officials. After this time, a series of committees was formed to prepare proposals for the Ministry, of which Sami served on one of the first. He was not the only individual I met with who served on these councils.

In the modern offices of the National Center for Diabetes, Endocrinology, and Genetics, I was able to meet with Ahmad, the immunologist. Ahmad also played an important role in the creation of the thalassemia prevention program: he served on one of the aforementioned committees of public health experts, as well as religious and youth officials, that produced guidelines for the Ministry of Health. Thus, Ahmad, as the sole representative of this center, represented a crucial perspective.

The form it has currently taken is not one that either Sami or Ahmad had originally supported. In the beginning, Sami did not envision that there would be a legal component, instead imagining a public education campaign. He initially worried that the law would rely too much on general awareness, but now thinks it “was not a bad idea” as

¹⁹⁹ Hamamy et al., “Communities,” 58.

it may have made it easier to implement the prevention program. For his part, Ahmad did not imagine that the testing would take place under such unregulated conditions. While on the committee he argued for a limitation on the laboratories allowed to perform the test: “I tried to make only certain laboratories, even in the Ministry of Health they are certified to do this, but unfortunately, I was not able to convince them.” The result was that it was extremely easy in the beginning of the program for any laboratory to obtain certification to perform the tests. Given the number of couples married each year in Jordan, which is around sixty thousand, Ahmad suggested that one good laboratory could have been selected to run the three hundred and thirty odd samples per day.²⁰⁰ Instead, there is no mechanism to assess the quality of the labs and whether they are using the equipment properly. The unregulated nature of the process also allows for private laboratories to bend the rules: “Sometimes they write report without doing it, they give both normal. To put normal, it is almost ninety-five percent you are true, okay? The problem is not them, but to find the abnormal, those five percent.” Ahmad explained that there was little that could be done about this: “The form is there, it is signed, written by X laboratory, you cannot do anything, whether it is fake or true. Unless those get married and later on they have found there is some problem with them. Then you can go back and look which laboratory did it...but that can take a long time.”

Families who know of a genetic disease within their family are most likely to attempt to fabricate test results. Mourad explained that they use *wasta*, or personal connections, to find private labs that are seeking to increase profits: “They use *wasta* to

²⁰⁰ Al-Hait, “Barnamaj,” 11.

do that. And some lab they said okay, I can save material, why should I do the testing if they want this result, there they go, and they still [have] the money. I mean it is a joke, but things happen.”²⁰¹ This is especially true for the family of the bride; if the bride is found to be “tainted” in some way, then there can be stigma attached to her. According to the 2009 Jordan Population and Family Health Survey, only nine percent of women have not married by the end of their reproductive years.²⁰² If a woman is unable to get married, she will very much be an outsider in Jordanian society. This stigma can also have long-term effects on the marriageability of other women in the family. Attempts to circumvent the tests are not necessarily restricted to the bride’s family. Ahmad added that the groom’s family could also have something to hide. Overall, Ahmad concluded that it was “not a very large problem.” Despite their limited nature, he wanted a centralization of the testing to improve quality control. While it is “good, acceptable,” it is not necessarily up to his standards.

Both Sami and Ahmad expressed concerns about the dearth of genetic services available in the country, an opinion shared by members of the Ministry of Health as well. The criticism of the quality of counseling was a recurring theme in almost all of my conversations with doctors and public health officials. Even for those who were happy with the overall success of the program, the counseling represented a cause for concern. In the following section, I will discuss the results of my investigation into the quality of genetic counseling for those who take the premarital test in Jordan. This is not meant to

²⁰¹ *Wasta*, derived from the word for intermediary and loosely meaning “clout,” refers to one’s connections and influence that are often used to get things done (especially in bureaucratic settings).

²⁰² Department of Statistics [Jordan] and ICF Macro, *Jordan Population and Family Health Survey 2007*, 59.

be an exhaustive evaluation of genetic services in Jordan. Rather, through these anecdotes, I hope to provide insight into the problems that this program has highlighted with the quality of these services in Jordan.

Genetic Counseling in Jordan: An Untrained Influence

In the basement of a building adjoining one of the many private hospitals in Amman is a molecular genetics testing laboratory. This laboratory tests for both infectious as well as genetic diseases, including beta-thalassemia. Most of its clients are outpatients from the hospital, but the laboratory also receives many referrals from around the region. As my informant Muhammad, one of the two molecular genetic specialists, explained, other facilities in the region cannot afford to invest in the necessary equipment.

Demand for the laboratory's services has increased dramatically, making the laboratory a profitable entity. In 2007, they tested about one sample per day. This has increased to twenty to thirty samples per day from Jordanians alone, plus another five from within the region. During our conversation, Muhammad received a call from someone in Syria asking about a test for spinal muscular atrophy. Much of this increased volume can be attributed to the premarital testing program for beta-thalassemia.

The laboratory uses the standard CBC and hemoglobin electrophoresis tests for beta-thalassemia. If these tests are not conclusive, then the additional genetic tests are performed at the laboratory to look for specific mutations. He explained that this later step helps the laboratory achieve a one-hundred percent accuracy in its tests.

Muhammad, although he suggested that he is likely the only holder of a Ph.D. in molecular genetics in Jordan who works in a laboratory, has not received any formal training in genetic counseling. Nevertheless, when the couples receive their results for the beta-thalassemia test, they often turn to him for help in interpreting them. Thus, despite his only experience in the matter being a few psychology courses during his masters program, Muhammad, the molecular specialist, becomes the genetic counselor. This is in direct violation of the program's guidelines.²⁰³ However, because of the lack of trained genetic counselors, the couples have few other options. Muhammad explained that he himself did not expect to counsel around two couples per day: "It just came with the work."

Muhammad's counseling sessions all assume the same general form. He begins by isolating the couples, taking them away from any other people in the laboratory. After offering coffee, Muhammad starts with friendly conversations, segueing into a discussion of the risks of beta-thalassemia. It is then that he continues with "unfortunately..." before outlining the percentage chance that their offspring will be affected and the serious consequences. The couples' responses range the gambit: some cry, some act calmly, some take it as a symbol of death. When asked what he would do for a crying client, Muhammad suggested that he would offer some tissues and a glass of water. Nearly all couples would ask him to check the test again; yet, as he explained, the tests had already been double-checked.

²⁰³ Al-Hait, "Barnamaj," 26.

In comparison to Downs syndrome, Muhammad suggested that discussing beta-thalassemia was “not that much of a disaster.” Nevertheless, he does not enjoy these conversations. When asked whether he felt qualified to handle these consultations, Muhammad offered that he does if he trusts himself. This is despite not being a physician, a qualification he stressed provides the necessary understanding of the “psychological effect” of genetic diseases.

When asked whether he supported the premarital prevention program, Muhammad explained that he tries to remain neutral. However, to prevent beta-thalassemia from spreading throughout the country, he puts an emphasis on “nothing else, just the truth” during these consultations. It is through these medical facts that he attempts to “scare” the couples into not going through with marriage. This is not the case for all couples. When asked whether he would hope that some people would choose not to get married he replied: “Sometimes.” If he perceives true love between the two individuals, perhaps seen through the holding of hands, he may be encouraging. His opinions on these matters are founded in “a kind of feeling,” based on as little as “eye language,” and they can determine how he presents the results of the test. In looking at the couples, Muhammad attempts to gauge “how strong they need each other, the love story between them,” and whether the couple appears to want to continue. After these consultations, he sits down with himself and reviews his decision. When asked to evaluate his performance, Muhammad responded that he felt he had the “right positions” most of the time.

If a couple chooses not to marry, there can be a serious stigma attached to the woman. Muhammad pointed out that it may be difficult for these women to find another husband. He suggested that in nearly half of the cases where the woman alone is found to be a carrier, her husband leaves. This is despite the nonexistent risk of having an affected child. He attributed this to a certain “mentality” or “habit” prevalent in Jordanian society. Muhammad is not the only ad hoc genetic counselor with whom I spoke.

Sami, in addition to his role in performing bone marrow transplants, is often pushed to advise couples. This is despite a lack of any official training in genetic counseling. Instead of going to the Ministry of Health, student couples often come to Sami’s office. Showing up unannounced, they seek to discuss their blood test results.

In these conversations, Sami similarly adjusts his approach based on perceived affection: “I sit with them and talk with them and if I feel they really would like to get married...then I do further testing. Otherwise, I’ll tell them listen, find somebody else.” According to Sami, those who receive this news do not respond dramatically: “They just consider it a hard day, bad luck...they do not usually continue with the process.” I asked Sami whether he felt that if he helped the couple make the decision, his counseling was then directive:

I don’t tell them frankly that they should not get married. But I explain to them clearly if they get married what exactly do they expect and whether they can put up with it or not and in order to make sure that they understand this they have to look, see, and maybe even meet individuals, that’s probably make life, their decision all the easier.

Many of my informants explained that they often brought in beta-thalassemia patients and families of children with beta-thalassemia to meet with carrier couples or

sent the couples to one of the thalassemia centers. The idea behind these encounters appears to be that this living evidence will dissuade the couple from continuing with their marriage plans. A similar technique can be seen in the inclusion of pictures of children with severely enlarged spleens, the result of poor disease management, in the brochures distributed to explain the program. This is part of the larger attempt, at least for Sami, to exert “indirect influence” on the couples. Given that most couples who speak to Sami decide not to get married, his influence may be more direct than he realizes.

His lack of formal training aside, Sami, because of his thirty-three years of experience in medicine, considers himself sufficiently “self-taught.” He explained that he has enough knowledge to teach a “101 or 102 class” in genetics. However, in reflecting on the program, Sami identified the primary weakness as a lack of trained genetic counselors. He concluded that there should be a government-run genetic counseling center in every major city to provide free advice to patients. This would not only be for beta-thalassemia, but for other genetic diseases as well. Sami explained that the program in Jordan was not “a complete program when it comes to counseling and individuals have to fish for counseling here and there.” Part of this problem appears to be economic.

One of Jordan’s only resources is its manpower. Without the necessary economic incentives, however, many educated Jordanians find themselves searching for work elsewhere. This is true for many fields, including genetics. In his laboratory at the National Center for Diabetes, Endocrinology, and Genetics, Ahmad loses more than half of his staff every year to Gulf states and the private sector. His employees can expect to make at least triple their salary at other jobs. Ahmad has mixed feeling about this: “At

least I train and the people, they find job. I'm not complaining, but my growing is slower [at my lab]. But at least I am serving other places. That's okay. This is the policy of Jordan in general."

These economics are especially challenging for a country attempting to develop a comprehensive genetics program. Ahmad explained that his own initiative has experienced setbacks: "We send many people to America for clinical genetics and they stay there. They are not coming back. This is a problem. We have two in Qatar now. They are paying them maybe ten times what we are paying them here, but they are in Qatar." The consequence of this is that the quality of genetic counseling in Jordan suffers. Ahmad added that he personally received many telephone calls from couples following up on the counseling they have received. The most common problem appears to be that the counselors interpret the reports wrong, declaring individuals to be normal when they are in fact carriers. This means that a couple may choose to marry and then, after being told that they are not at risk, have a child with beta-thalassemia. I asked Ahmad what the Ministry of Health was doing to improve the number and quality of counselors in Jordan. He could not point to anything and suggested that the Ministry was probably doing nothing. In an attempt to confirm this, I sought out officials at the Ministry.

The Ministry of Health's new building is an impressive tower of large white stone. Located in the northern part of the city, this gigantic complex has served to unify the ministry's various branches. Inside, the finishing leaves something to be desired. As is the case with many of the modern complexes built in the Arab world, it seems that the money ran out before the project was finished. The office hallways were remarkably

bare; pieces of paper taped to the door served as name plates. It was in one of these offices that I met with Bassem, the Ministry of Health doctor who works at the Ministry's genetics and congenital diseases department

After the customary offering of tea and coffee, we began the interview. Despite prefacing that his English would disappoint, Bassem talked at length in a slow, steady voice about the program, its goals, challenges, and successes. In our conversation, he displayed a knowledge of the initiative that exceeded that of all of my other sources. At the same time, he portrayed an apparent ignorance of some of the key problems identified by others. This was especially true for genetic counseling.

According to Bassem, there is no problem with the quality of genetic counseling offered in Jordan as part of the premarital testing program. He emphasized the "yearly and regular" workshops that the Ministry of Health puts on to train doctors in how to speak to patients and to keep "up to date." Bassem added that there was an ethical component to this as well, something necessary because of certain characteristics of the Jordanian people: "We are emotional people and believe me, those couples they have a strong relation and love with each other and it is bad to hear such news. So the focal point who provides this information has a lot of training on how to talk to them." Bassem himself conducts conversations with couples who are intent on marrying. His office is at one of the seven official counseling centers identified by the Ministry of Health.

Bassem often invites both the couple and their families to the counseling session. Similarly to Muhammad, he sits the families down for coffee and a chat, "like friends."²⁰⁴

²⁰⁴ The inclusion of the family members may be in recognition of the high rate of arranged marriages. It may be interesting to reflect on how the inclusion of additional individuals affects the counseling practice.

He has a clear goal with this approach: “To gain their trust and to explain...this is for your benefit. It’s not against your will....so by that, you gain their trust and they believe that you are working for them.” Bassem is not necessarily “working for” the couples’ marriages. When I asked Bassem whether he hoped that the couples would not get married he responded affirmatively: “As a doctor, yes, definitely I believe that if I prevent such a case and what it will have from suffer....I’m sorry to say that it’s a miserable life for the patient, for the parents, and those who have good vision, highly educated, they know that what waits for them is really great suffering.” According to Bassem, his calming approach works to dissuade most couples from pursuing marriage.

I was able to catch a glimpse of Bassem counseling while he showed me around at the laboratory of the Ministry of Health’s Amman comprehensive health clinic. The lab, one L-shaped room, was staffed by three nurses. At one of the sides of the room, a glass window with a slot underneath served as the walkup counter for those seeking a blood test. As Bassem was introducing me to the two laboratory technicians responsible for drawing the blood and performing the tests, a man came up to the window and asked for clarification on his test results. Bassem informed him that he was a physician and after briefly looking over the document for a few seconds, told the man that he would have to get further testing; Bassem provided no additional explanation. It seemed to be a case of “drive-through counseling” and again suggests a lack of resources for genetic counseling. I came across further evidence of this deficiency in my conversation with Huda.

Like many of her colleagues, Huda is pushed into the unexpected role of being a genetic counselor. Although she has only been at the center for three months, she has already seen a few couples, without the benefits of any training or workshops. When I asked her if she felt qualified to give this counseling, she did not express confidence. Although she has an understanding of autosomal recessive disorders and basic inheritance patterns, she does not know much beyond this. When forced to talk to the patients, she takes one of two approaches. If the woman is a carrier, then she does not tell “all the information.” This is because of the stigma that these women can face: “It will create more problems for this woman, so just to make her life easier I will try to solve her problem by herself...I call the mother and I call her to come and discuss the problem.” As for males who are carriers, she simply offered “I will explain it frankly.”

Huda expressed a general approval for the initiative: “It is very successful program, it is [an] excellent program.” Nevertheless, she hoped that there would be improvements in the level of counseling provided. For as she recognized, her knowledge as a general pediatrician is limited. She also made a unique observation as to a gap in the testing program. For those who receive their reports and find out that they have abnormal hemoglobin levels, there is no follow up from the Ministry of Health. Female patients with low hemoglobin levels can have problems during pregnancy and there is no system to manage this risk. Huda explained that patients are reluctant to follow up: “Once they are able to walk and go and come they will not ask for doing more investigation or to know what the problem they are having.”

Before I left, Huda asked to exchange email addresses so that I would be able to update her about any genetic counseling workshops or send materials that might be of help to her. When I asked about the workshops Bassem had mentioned to me, she confessed she had never heard of any. Since she only had been working for three months, it is understandable that she may have missed one of these “regular” workshops.²⁰⁵ Nevertheless, it appears problematic that without this training, she has been performing the duties of a genetic counselor. This again suggests that Bassem’s assessment of the quality of genetic counseling at the Ministry of Health was, at best, overly optimistic. More likely, it emphasizes the improvisational nature of the initiative.

In all our conversations, Bassem displayed an immense pride and confidence in the premarital program and its supposed sophistication. This can be seen in the access that he gave me at the clinic. Not only did he allow me to interact with children he was seeing as part of his duties at the Phenylketonuria (PKU) clinic, but he also provided me with a copy of the CBC tests for one couple. In his rush to have the document copied, he did not even have the two individuals’ national identification numbers crossed out. The same level of confidence was also clear in our discussion of genetic counseling in Jordan.

I asked Bassem whether there were any individuals with advanced degrees in genetic counseling practicing in Jordan. He responded “definitely,” adding “we have a lot [of genetic counselors] here in Jordan.” Bassem continued, maintaining that one could find well-qualified, Ph.D. carrying genetic counselors in all sectors of the Jordanian

²⁰⁵ I did find one other mention of these genetic counseling workshops in the literature (Hamamy and Al-Hait, “Premarital Screening Program for Beta-Thalassemia in Jordan.”). This was a reference to a joint WHO-Ministry of Health initiative that sponsored workshops for three genetic counselors from each of the fifty-three comprehensive health centers in Jordan, beginning in August 2006 (Ibid.). It is unclear both how effective these workshops have been and the degree of overlap between those who went to these workshops and those who practice genetic counseling.

health system. When I posed a similar question to Mourad, he provided an insightful response that may explain Bassem's perspective:

Not as far as I know. It depends if you ask somebody else in Jordan, he'll tell you we have a hundred genetic counselors in Jordan. To me, genetic counselors [are those] who finish program three years in a good college in the States and certified. So depend how you define genetic counselors. To me, there is no. To them, they might tell you we have hundred and they mean by this probably a nurse who can pronounce autosomal recessive not a genetic counselor.

Despite Bassem's statements, the Ministry of Health appears to be aware of deficiencies in genetic counseling, as well as many other problems with the premarital prevention program. In the 2009 booklet on the program, the following concerns are identified: a severe shortage in the number of genetic counselors, the disappearance of couples after the first test (i.e. CBC), approved laboratories not understanding initial results, insufficient public understanding, discrepancies in results from the same laboratory, false information being provided to couples, and people getting married without displaying a certificate of testing.²⁰⁶ In response to all of these difficulties, the Ministry of Health has suggested the following steps to improve the program: using hemoglobin electrophoresis as the one and only test for beta-thalassemia, providing better specifications for laboratories, improving communication between the laboratories and the Ministry, and involving religious leaders by having them provide the laboratories with the names and identity numbers of those seeking to marry.²⁰⁷ It is unlikely that Jordan will be able to implement these suggestions soon; only twelve devices for hemoglobin

²⁰⁶ Al-Hait, "Barnamaj," 14-20.

²⁰⁷ Ibid., 21.

electrophoresis are available in all the central laboratories and this is not enough to cover the demand.²⁰⁸ Even if there was enough laboratory equipment and personnel trained to use it, the program would be severely limited by the dearth of genetic counselors, a factor not addressed in the above recommendations. While the quality of genetic counseling may not necessarily affect the number of new cases of beta-thalassemia, it still is of vital importance to the ethics of the program. Thus it must be taken into account when assessing the initiative.

Stepping Back: Evaluating the Prevention Program

I asked many of the individuals whom I met with to evaluate the prevention program for beta-thalassemia in Jordan. Nearly all of them expressed positive opinions. This is despite most of them not having any data on whether the program had achieved a reduction in the number of new cases, a common metric for success. Mourad stood out as the lone dissident. While he had been involved in providing recommendations for the program in its early days, he had not been invited back to any meetings of the national committee of genetics for some time. Mourad attributed this to his habit of “frankly speaking.” Outside of the capital and no longer in contact with the Ministry of Health, he opined that, if anything, the incidence rate may have gone up. This is because carrier couples may continue to marry without sufficient knowledge of the risks of thalassemia.

At the Ministry of Health, Bassem explained that he was “proudly” and “loudly” saying that the program was a success. However, he was reluctant to share any specific

²⁰⁸ Ibid.

numbers with me, citing privacy concerns and the nascent nature of the program. I spoke by phone with perhaps the most prominent thalassemia doctor in the country, Doctor Bassem Kiswani, the head of the Jordanian Hemophilia and Thalassemia Society and the thalassemia department at Al-Bashir.²⁰⁹ He informed me that the number of new cases of thalassemia in Jordan had dropped by fifty percent since 2004; he has provided similar numbers on other occasions.²¹⁰ This is certainly an achievement and, given the age of the program, a rapid one. However, it is unclear whether the rate will continue to drop.

In both Cyprus and Iran, the premarital prevention programs have resulted in a dramatic reduction in the number of new cases of beta-thalassemia each year. Similarly, an often cited voluntary screening program started in Sardinia in the late 1970s combined with extensive education efforts has resulted in a ninety percent decrease in the number of beta-thalassemia major births.²¹¹ All three of these programs have achieved success using a combination of free prenatal diagnosis and selective abortion.²¹² While the initial results from Jordan's program appear promising, it is unclear whether without an increase in the availability of prenatal diagnosis and the option of early termination they will continue to improve. As mentioned above, the Ministry of Health is aware that the program in Jordan is in need of change. Nevertheless, even if it is able to raise the quality

²⁰⁹ I should clarify that this is not the same Bassem I refer to elsewhere in the work.

²¹⁰ Malkawi, "Anti-Thalassemia Efforts Undermined."

²¹¹ Zlotogora, "Population Programs," 248.

²¹² These program also featured successful education campaigns (Cao, "Results for Programmes," 169). I was unable to find any comprehensive data on awareness of thalassemia amongst the Jordanian public. Mourad suggested that there was some education in public school on genetics and thalassemia, but he doubted its effectiveness. The Ministry of Health booklet identifies a lack of sufficient understanding in society as a constraint of the prevention program (Al-Hait, "Barnamaj," 14). This indicates that public education is another area for improvement within the program.

of genetic counseling and diagnostic methods, it is uncertain how great of an impact this will have.

The program in Jordan is based on other successful initiatives. However, the lack of involvement of religious leaders, limits on abortion, patient-borne cost of prenatal diagnosis, and lax testing policies all mean that it is not exactly following in their footsteps. Mourad lamented the differences between the Jordanian program and its foreign predecessors, declaring “we don’t need to reinvent the wheel.” Given the nature of the initiative in Jordan, the government may only be creating a more broken one. A potential explanation for this may be found in the history of the program. While following the example of other countries, Jordanian officials may also be hoping to coin their own idiosyncratic approach. The specific Jordanian context does call for efforts at localization. Nevertheless, in seeking to define the program against other initiatives, public health officials may be doing more harm than good. This is not only because the program may not continue to decrease the number of new cases.

There are many possible metrics for evaluating genetic disease prevention programs. Much of the literature focuses on numbers of new births as well as cost.²¹³ Given the documented expense of treating thalassemia, it is almost certain that the program in Jordan is cost-effective. In Cyprus, the cost of prevention for the whole of the year 1984 was equal to the total cost of treatment for just eight weeks.²¹⁴ The cost of prevention in Greece was equal to the cost of treating one newborn for one year.²¹⁵

²¹³ See Cao et al. “Screening for thalassemia: A model of success” and Angastiniotis, Kyriakidou, and Hadjiminias “How thalassemia was controlled in Cyprus” for two such examples.

²¹⁴ Angastiniotis, Kyriakidou, and Hadjiminias, “How Thalassemia was Controlled in Cyprus,” 296.

²¹⁵ Cao, “Results for Programmes,” 175.

Perhaps it is equally as important, however, to evaluate this program on an ethical level. Regardless of the future success of the program in reducing new cases and costs, this initiative poses particularly pressing questions of ethical significance. These are vital to assessing the program and understanding how “broken” the Jordanian wheel may be.

I will focus on two of these ethical questions. While they are certainly not the only ethical ambiguities surrounding this program, they both have wide-ranging implications of particular import for understanding public health initiatives for genetic diseases. The first is the ethical impact of the poor quality of the genetic counseling that is mandated by the program. On first inspection, the attempts by ad hoc genetic counselors such as Mohammed to selectively “scare” the couples into not marrying may appear problematic. In the next chapter, I will focus on a reexamination of the principle of neutrality and nondirectiveness in counseling. Additionally, I will examine the program’s effect on consanguineous marriage. Consanguineous marriage is an important tradition in Jordan and its practice can perhaps be viewed as the expression of a vital human freedom.

I will begin the chapter with a discussion of the history of genetic counseling and the evolution of the principle of nondirectiveness. Afterwards, I will move onto an evaluation of the genetic counseling provided as part of the program in Jordan and how it compares to its own, as well as more universal standards. I will then conclude with an examination of the consequences of the directiveness of the initiative and its likely effects on the tradition of consanguineous marriage.

Chapter Five - The Ethics of the Prevention Program

Genetic Counseling: Public Health and Nondirectiveness

Genetic counseling has its origins in the American eugenics movement. From the late 1880s to the late 1940s, an assortment of clinical psychologists, biologists, and social scientists, as well as a few physicians, attempted to purify the American population through applied genetics.²¹⁶ This highly coercive social campaign used laws to control immigration, procreation, and marriage in an attempt to reduce the burden of the “unfit” on society.²¹⁷ Unsurprisingly, nondirectiveness was not a feature of the counseling practiced at this time.²¹⁸ This movement largely fell out of favor after World War II with the exposure of the Nazis’ perversion of the ideology. The new era of genetic counseling that followed experienced a shift of the profession into academia.²¹⁹ Client autonomy began to take precedence in the mind of genetic counselors.²²⁰ Nondirectiveness emerged as a core principle of genetic counseling, not least as a way to distance the profession from eugenics.²²¹

The late 1960s marked the first attempts to develop training programs and certification systems for genetic counseling.²²² Geneticists also began trying to define the

²¹⁶ Sorenson, “Genetic Counseling,” 4.

²¹⁷ Ibid., 4-5.

²¹⁸ Ibid., 5.

²¹⁹ Ibid., 6.

²²⁰ Walters, “Ethical Obligations,” 133.

²²¹ Rantanen et al., “What is Ideal Genetic Counselling?,” 446.

²²² Sorenson, “Genetic Counseling,” 9.

profession; the term “genetic counseling” had only been coined by Sheldon C. Reed in 1947.²²³ The first and most prominent of these definitions to emerge was presented in 1974 by Frank Clark Fraser in the *American Journal of Human Genetics*:

Genetic counseling is a communication process which deals with the human problems associated with the occurrence, or risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained person to help the individual or the family to comprehend the medical facts, including the diagnosis, the probable course of the disorder and available management, to appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives, to understand the options for dealing with the risk of recurrence, to choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision, and to make the best possible adjustment to the disorder in an affected family member and to the risk of recurrence of that disorder.²²⁴

This definition, a direct attempt to move the field away from links to social hygiene, emphasizes nondirectiveness. Counselors are obligated to “act in accordance” with the decision of the individual and their family, not to make it.²²⁵ The counselor’s duty is one of providing facts, not decisions. An update to this definition, approved by the National Society of Genetic Counselors in 2003, makes sure to stress that genetic counseling “is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.”²²⁶ This process includes “interpretation of family and medical histories...education about inheritance, testing, management, prevention, resources and research...counseling to promote informed

²²³ Ibid., 8-9.

²²⁴ Fraser, “Genetic Counseling,” 637.

²²⁵ Ibid.

²²⁶ Resta et al., “A New Definition of Genetic Counseling,” 77.

choices and adaption to the risk or condition.”²²⁷ Today, American genetic counselors almost exclusively follow the principle of client autonomy; their counseling is to be value-neutral and nondirect and it must respect the decisions of the individual.²²⁸ Healthcare ethicist Karen Gervais explains that, following the model of the doctor-patient relationship, the counselor is seen to be the “fact provider” and the counselee the “value provider.”²²⁹ Bioethicist Arthur Caplan refers to this as the “ethos of value neutrality.”²³⁰ This approach has been used in beta-thalassemia prevention programs. Iran’s initiative is based on the WHO’s standards which firmly support nondirective counseling.²³¹

In 1998, the WHO proposed international ethical guidelines for medical genetics and genetic services. The document takes a clear stance on directiveness: “Genetic counseling should be available to all, and should be as nondirective as possible.”²³² For the WHO, nondirective counseling has two important components: the provision of “full and unbiased information” and the establishment of an “empathetic relationship that offers guidance and helps people to work to their own decision.”²³³ This later part is especially important as individuals and families often are forced to rely on their

²²⁸ Gervais, “Objectivity, Value Neutrality, and Nondirectiveness,” 119. There was not always this uniformity in the field. Writing in 1974, Fraser suggests “opinions differ widely on how directive genetic counseling should be” (649) While some believe that counselors should stop after providing a risk assessment, others advocate an explicitly paternalistic approach; most counselors are in the middle (Ibid).

²²⁹ Ibid.

²³⁰ Caplan, “Neutrality is Not Morality,” 149.

²³¹ Samavat and Modell, “Iranian National Thalassaemia Screening Programme,” 1135.

²³² WHO, *Proposed International Guidelines*, ii.

²³³ Ibid., 5.

counselors for accurate information and advice.²³⁴ Ultimately, while the counselors do not tell the individuals what to do, they should, “as much as possible, support all decisions.”²³⁵ The prevention program in Jordan is based on similar principles.

In the booklet on the program, Sana Al-Hait, a recently retired clinical geneticist from the National Center for Diabetes, Endocrinology, and Genetic Diseases, provides guidelines for those counseling as part of the initiative. She makes sure to stress some basic rules, such as showing patience, preserving confidentiality, and sitting down with the couples, as opposed to staying behind the desk.²³⁶ There is also an emphasis on respecting culture and beliefs, as well not casting blame on individuals for their habits.²³⁷ In her guidelines, Al-Hait provides an explicit definition of nondirective counseling: “Explain information and do not suggest to them any behaviors. We are to explain the possibilities of reproduction, giving them their right to make their choice. This is what is meant by nondirective counseling.”²³⁸ These instructions are echoed in a pamphlet distributed by the Ministry of Health in 2009: “The genetic counseling respects the opinions of people and their beliefs and does not dictate any specific behavior to

²³⁴ Ibid.

²³⁵ Ibid.

²³⁶ Al-Hait, “Al-istisharah,” 45.

²³⁷ Ibid.

²³⁸ Ibid. The Arabic text is as follows:

Sharḥ al-ma‘alwumāt wa-‘adam al-iyḥā’ lahum bi-ay sulūk, ‘alaynā sharḥ iḥtimālāt al-injāb, wa-i-‘aṭā’hum ḥaqqhum fī qarār ikhtiyārhum. Wa-hadha mā y’anī an al-istishārah al-warāthīyah takun ghayr mubāshirah.

them.”²³⁹ It appears that those performing genetic counseling in Jordan do not adhere to these guidelines and similar international standards of value-neutral counseling.

Muhammad’s attempts to “scare” couples into marrying are a clear example of directive counseling. Nevertheless, he reminded me that ultimately “you are free just to take the decision.” While Muhammad does his best in many cases to stop couples from marrying, they are not bound to follow his advice. At the Ministry of Health clinic in Amman, Maha similarly emphasized that she preserves the essential respect for autonomy. She was adamant that it was “not our job” to tell the couples what they should do. At the same time, she admitted that the staff does inform the couples “if we are in your place we will not get married.” This is a clear passing of moral judgment. Huda was more explicit about her attempts to do as much.

It was clear to Huda that having a child with thalassemia was an outcome to be avoided at all costs. While she had not yet come across a case of two carriers hoping to marry, she had an idea of the approach she would take with them:

Yes...I’m telling you till now I have’t get across such cases but I think if they are both carriers I will just yes I will put my influence not to get married because this will create problems for them in the future and I will try to give them examples about what future they will have concerning thalassemia, blood transfusion, and problems of hemosiderosis...it will be a terrible life for them and their children and lifespan will be reduced...I will make them feel that it is not an easy job to do it...this is in my mind if I have the chance to do it.²⁴⁰

²³⁹ Jordanian Ministry of Health, Directorate of Noncommunicable Diseases, Department of the Prevention of Genetic Diseases, *Barnamaj Al-Fahaş*. The Arabic text is as follows:

Al-istishārah al-warāthīyah tahtaram ārā’ al-nās wa-mu’ataqadāthum wa-lā tamlī ‘alā al-nās ay sulūk mu’ayyn.

²⁴⁰ Hemosiderosis is a disorder caused by iron overload.

Sami appears to employ similar tactics: “I don’t tell them frankly that they should not get married. But I explain to them clearly if they get married what exactly do they expect and whether they can put up with it or not and in order to make sure that they understand this they have to look, see, and maybe even meet individuals. That’s probably make life, their decision all the easier.” I asked Sami whether this meant his approach was directive: “There’s indirect influence in this, I agree.”

Mourad was even more straightforward about the role of Jordanian genetic counselors in the process: “We do discourage people to get married if they are carriers. Clearly.” In an attempt to provide a strong example of the risk, Mourad sometimes brings in individuals affected with beta-thalassemia: “Once in awhile we show them other thalassemia patients from other families and look at this, are you willing to go carry this package?” I asked Mourad whether he thought that he influenced the couples’ decision. He took for granted that influencing was the ideal and lamented its limitations: “Not as much as we hope because most of the cases we did this with them they still get married.” Fatima was also skeptical of the counselors’ power: “We just advise them, if they have it in their mind, you will not change this attitude.” Given that forty percent of couples decide not to get married, it seems the counselors are capable of influencing these decisions.²⁴¹

Sami, appealing again to the burden of beta-thalassemia, did not see any ethical problems with counselors exerting influence:

²⁴¹ Al-Hait, “Barnamaj,” 20.

I don't because I think, I think with what we see and since most individuals are heading for a smaller family, in order to have a family with beta-thalassemia major, it's a nightmare I tell you. It's a huge burden on the family to get transfusions, monthly, or even two weeks, to find donors, to find complications related to iron overload treatment, BMT, chance of losing a child...these are issues which are extremely unsettling for the couple. If they can have a child without this, this is what they should be looking for. But obviously there are individuals who are, they just love each other, they just want to get married. They are ready to put up with whatever comes out of this.²⁴²

I asked Sami why people, perhaps besides love, decided to continue with their marriage:

The great majority because of ignorance and they have not seen probably a relative or person in the family who has this and this is why they don't know how much suffering there is, these accidental individuals meeting whatever at work or during studies and both are carriers and they do not know the exact implications of being thalassemia major. This is why one needs to sit with them and tell them exactly what risk they are taking.

This seems to represent a view shared by all of my informants and reflects the wider ethos of the program. The firm conviction with which these ad hoc genetic counselors view the negativity of beta-thalassemia guides their counseling. Specifically, in explaining the risk of marriage, the counselors abandon the principle of nondirectiveness and attempt to influence the couples.²⁴³ Neither the counselors nor the law prevent the couples from marrying. At the same time, this influencing means they are stepping outside the role of mere educators. This is against international standards for counseling, the WHO guidelines, and the instructions set forward by the Ministry of Health. Given the structure of the initiative, it is unsurprising that the genetic counseling practiced as

²⁴² BMT stands for bone marrow transplant.

²⁴³ An interesting, though perhaps tangential, point to consider is whether just in bringing in families with children affected with beta-thalassemia to meet with the couples, the counselors are breaking the principle of nondirectiveness. This is because of the inherent subjective opinions the families would be sharing about the disease. An examination of this topic may prove useful for further work on nondirectiveness in counseling.

part of this program is directive. There are a number of incentives for those performing genetic counseling to exert their influence on couples.

Abortion is not legal in Jordan for a fetus affected with beta-thalassemia. Furthermore, there is no penalty for carrier couples having children. The government will still provide treatment free of cost to the affected offspring. According to Muhammad, couples will only pursue marriage in Jordan if they are planning to have children. Fatima explained that although some individuals intend on getting married and not having children, they rarely follow through with this. Sami declared the idea “unheard of.” Adoption as well is not widely practiced in the Muslim world. From a public health perspective, given the moral and economic cost of preventing beta-thalassemia after conception, limiting marriages of carrier couples is the only way to effectively limit the number of new cases. In choosing this approach, public health officials are making a value judgment inherent to their discipline.

Public health is not a value-neutral field; its goal is for populations to adopt healthier lifestyles, often accomplishing this through surveillance and control.²⁴⁴ The combination of genetic counseling and public health, and the status of some of the genetic counselors as public health officials, seems to create a fundamental tension within this program. For the individuals who are supposed to be providing unbiased and nondirective advice to the couples are also motivated by a belief in the need to prevent their marriages. This directiveness in counseling is not necessarily unethical; it is an approach common in much of the medical world. As Caplan notes, most areas of

²⁴⁴ Atkin and Ahmad, “Genetic Screening and Haemoglobinopathies,” 454.

medicine and public health “make no pretense of value neutrality.”²⁴⁵ A cardiologist would be admonished by his or her colleagues if, citing the principle of patient autonomy, they did not provide a treatment recommendation for a person’s high cholesterol level.²⁴⁶ Genetic counselors, however, would be severely criticized for challenging a client’s decision.²⁴⁷ In the case of the Jordanian program, one’s first instinct may be to reprimand Muhammad for attempting to “scare” his clients into not marrying. This is probably because of the sense of infringing on personal autonomy. Medical ethics is built upon a balance between autonomy and beneficence. In Jordan, the costs associated with the treatment of beta-thalassemia—economic, physical, and mental—may outweigh the possible negative effects of limited autonomy. The Jordanian government clearly made this value judgment in starting the initiative and it is unclear how the ethos of neutrality and idealized patient autonomy in counseling fits into this larger goal.

Directive, genetic screening programs are not necessarily unethical. In providing more than just the facts, genetic counselors can be of greater help to their counselees than automated risk assessment robots.²⁴⁸ From a public health perspective, great benefits, in the form of a reduced burden on society, can be achieved with minimal harm to individuals. In Jordan specifically, on first glance, the consequences of couples splitting appear to be some individuals not getting married and possible stigma for the family. These outcomes can seemingly be largely avoided with increased health education.

²⁴⁵ Caplan, “Neutrality is Not Morality,” 152.

²⁴⁶ Ibid.

²⁴⁷ Ibid.

²⁴⁸ Ibid., 160 and Fraser, “Genetic Counseling,” 650.

However, the Jordanian initiative also seems to have the consequence of moving against an important social tradition. When making value judgments in starting public health initiatives, it is important to be aware of these wide-ranging consequences.

Consanguineous Marriage: Individual Right and Public Wrong?

There appear to be clear social benefits to consanguineous marriage. As I outlined in the chapter on consanguinity, the tradition seems to serve to strengthen social bonds, maintain wealth, improve the quality of life for the women, and preserve family identity.²⁴⁹ There is also an obvious health cost to the practice.²⁵⁰ This risk is not as great as is often perceived in the West, America particularly.²⁵¹ Nevertheless, the prevalence of congenital and genetic diseases in the Middle East underscores the medical challenges that can arise in populations with high maternal age, large family size, and an elevated rate of consanguineous marriages.

The individuals who I spoke with in Jordan were almost universally dismissive of the tradition. Mourad was one of the few who even suggested that the tradition would be missed. This most likely reflects the educated, urban bias against consanguinity. The continued, although apparently declining, prevalence of consanguineous marriages in Jordan suggests that not all Jordanians share this view.²⁵² Given the documented negative health effects of the tradition, it is obvious why public health officials and doctors would

²⁴⁹ Teebi, "Introduction," 4 and Inhorn et al., "Male Infertility and Consanguinity in Lebanon," 181.

²⁵⁰ Modell and Darr, "Genetic Counselling," 227.

²⁵¹ Strauss, "Genetic Counseling for Thalassemia," 368.

²⁵² Department of Statistics [Jordan] and ICF Macro, *Jordan Population and Family Health Survey 2007*, 67.

be against the practice. This bias is clear in the design of the program. For it appears that the only way for the program to be successful in reducing the number of new cases or cost of treatment is to decrease the number of consanguineous marriages.

The Jordanian initiative does not prevent carrier couples from marrying. This is a point that my informants were always sure to stress. Mourad even suggested that this forced separation might “interfere with human rights.” Nevertheless, it is clear the program can only succeed if these couples do not marry. As mentioned above, almost no individuals marry without planning to have children. Thus, without the legal option of abortion for an affected fetus and the impracticality of abortion, the program will only be effective if it succeeds in splitting carrier couples. This seems to create a fundamental tension surrounding consanguinity. For the individuals who are most likely to both be carriers are those who are both from a family with a history of the disease. If viewed in this way, it appears that the prevention program is an implicit move against the tradition of consanguinity.

I presented these thoughts to many of my informants in Jordan. Perhaps surprisingly, they readily confirmed that the program targeted consanguineous marriages. When I asked Bassem whether one of the goals of the initiative was to reduce the consanguinity he responded positively: “Definitely, it was the main cause to have thalassemia major.” The law does not “frankly” state this point. Rather, Bassem suggested that it was a “by the way.” Mourad concluded that the program must lower the amount of consanguinity: “It has to, otherwise it won’t work.”

Ahmad explained how lowering consanguinity fit into the priorities of the program: “It was not the first or the second or even the fifth objective...it is a hidden objective, you cannot put it as an objective in writing. But between the committee it was, yes, it was one objective, which is as it is, hidden objective, you can’t publicize that.” He did not see any ethical problem with this, as “we are not telling them not to get married.” It is clear, however, that the genetic counselors are acting on a desire to reduce the amount of “suffering” in the country by limiting new cases of beta-thalassemia. The economically forced overlap between genetic counselor, public health official, and doctor, as embodied in Bassem, as well as the incentives listed above, culminates in a “nondirective” body with a strong desire to influence. I asked Sami whether he thought people in Jordan had the right to have a child with thalassemia. His response speaks to the value judgment inherent to the program:

According to the Jordanian law and constitution they have every right to have kids with thalassemia. But then we can have considerable pressure on individuals not to have them because after all we as a nation have to take care of these individuals and we have to spend a lot of money and we are a poor nation and we cannot afford to continue spending money on them and therefore we can exert considerable pressure on these individuals not to have children with thalassemia.

Given these societal pressures, it is unsurprising that the counselors provide advice that is more than neutral. As I have discussed earlier in this chapter, neutrality is not necessarily the most ethical choice. In this specific case, however, there are potentially clear negative consequences to the success of the program. As currently constructed, there is a fundamental correlation in the program between the elimination of beta-thalassemia

major and the disappearance of a persistent social tradition. This is not necessarily an unethical framework.

There are plenty of examples of governments regulating individual behavior, especially in the name of reducing the overall public health burden. Perhaps the most prominent instance of this is the new wave of public smoking bans. These initiatives, like the premarital prevention program for beta-thalassemia, seek to protect the general public from the risky choices of individuals. The concern may be secondhand smoke in cafes in one instance and increased tax burden in the other, but the fundamental principle is the same. In the case of the smoking ban, one might argue that this is no serious move against individual freedoms. Similarly, one may suggest that in asking two people who are engaged not to marry, there is no fundamental infringement on human rights. This is because of the officially non-coercive nature of the program. The important difference between these two public health programs lies in the degree of disclosure.

In the case of the smoking ban, the goals and the methodologies of the initiative are clear to the public. This is not true for the premarital prevention program. While the explicit goal is the reduction of the new cases of beta-thalassemia, the implicit means to achieving this is the reduction of the number of consanguineous marriages. This is not an unintended consequence. Rather, as evidenced in my interviews, the people who are carrying out the genetic counseling as part of this program are aware and supportive of this aspect of the program. Even this is not necessarily unethical.

The argument as presented by the public health officials appears to be that there is no significant benefit to consanguineous marriage. In this respect, it mirrors the

justification for the smoking bans. This argument is not necessarily false; it is a normative claim. If one takes their words to be true, then there is no clear benefit to the practice. Viewed in this way, it may seem that there is no harm to targeting these marriages. This debate, however, should not be settled before the start of the discussion. Given the statistics from Jordan, it is clear the population who engages in consanguineous marriage is at least a significant minority.²⁵³ Their lack of presence in the public health sphere should not mean that they are specifically targeted. Those affected populations should be included in the conversation.²⁵⁴ One may argue that those most commonly partaking in these marriages, such as the rural poor, would not understand the public health benefits and thus risk jeopardizing the success of the initiative. If the reason that the program is implicitly pursuing this goal is because it seeks to avoid public discussion, then it is likely not on the strongest moral footing. Thus, the ethical problem does not surround the tradition of consanguinity, but rather the lack of transparency around the program's aims.

It remains unclear whether this program will succeed in limiting the number of consanguineous marriages. Bassem himself suggested “we won’t change the tradition here in Jordan.” However, if the program is effective, then it will necessarily have to change this practice. It is likely that if this goal were made explicit, that there would be dissent. The mere presence of dissent does not warrant the canceling of a public health program.²⁵⁵ However, it deserves special consideration, especially if raised by a particular

²⁵³ Khoury and Massad, “Consanguineous Marriage in Jordan,” 772.

²⁵⁴ I am not, however, suggesting any specific mechanism for incorporating public opinion. This is a complex issue, requiring a delicate balancing of individual and community rights and preferences, and I do not possess any simple solution.

²⁵⁵ Kass, “An Ethics Framework,” 1781.

subgroup.²⁵⁶ In the case of Jordan, it seems likely that poor, rural populations would be disproportionately affected by this initiative; this is because of their higher rates of consanguineous marriage. Furthermore, it does not appear the public health officials are taking their views into account. This is emphasized in the implicit nature of the move against consanguinity. Premarital testing programs do not have to treat consanguinity in this way. Tunisia takes an explicit approach; it mandates premarital genetic counseling for all consanguineous couples.²⁵⁷ The Jordanian government must be honest about its intentions, even if this temporarily limits the numerical success of the program. Otherwise, the initiative fails on the perhaps more important, ethical scale.

The program in Jordan highlights deep ethical issues in genetic screening prevention programs. Specifically, it underscores the difficulties surrounding the question of nondirectiveness and value neutrality in counseling and the regulation of social behavior. In the following section, I will conclude with a summary of my examination of Jordan's premarital prevention program and provide recommendations for ethically preventing genetic diseases. These are not intended to be comprehensive guidelines. Nevertheless, they build on the lessons of the Jordanian initiatives and suggest important considerations for all genetic screening programs.

²⁵⁶ Ibid. I did not hear complaints from any people about the program and its effect on consanguinity. However, it seems likely that one might hear this outside the main cities. This would be a good point for further exploration of the issue.

²⁵⁷ Chaabouni-Bouhamed, "Tunisia," 319.

Conclusion

In this thesis I have explored the case of the premarital prevention program for beta-thalassemia in Jordan. I began with an examination of the history of Jordan, establishing the important political and social context behind the program and highlighting the dearth of genetic services in the kingdom. Then I examined the tradition of consanguinity, both on a global as well as local level, keeping in mind the apparent social benefits as well as demonstrated health costs. The insights provided by my informants proved especially useful in understanding Jordanian attitudes among medical and public health officials to consanguineous marriages. Finally, I discussed the program in Jordan, focusing on questions surrounding abortion and the quality of genetic counseling. In an attempt to move beyond a basic statistical evaluation of the program, I utilized qualitative research to assess the initiative on an ethical level. This is an important metric for success for the program and one that is not sufficiently emphasized in the literature.

My focus was on two major ethical issues: the directiveness of the genetic counseling and the implicit move against the tradition of consanguinity.²⁵⁸ As I discovered in my time in Jordan, the counseling as practiced in Jordan defies universal, as well as locally adopted standards for neutrality in counseling. I concluded that this is an unsurprising result, given the existing incentives for genetic counselors to be directive as

²⁵⁸ Further exploration of aspects of confidentiality and consent, as well as patient autonomy and government regulation of individual behaviors, would also likely yield valuable results. This is not to mention a consideration of where genetic testing should stop; this is especially important given our increasing ability to select for specific traits (see the premarital testing organized by Orthodox Ashkenazi Jews for an interesting case study). Public health will surely grapple with these issues for years to come.

well as the value judgments inherent to public health. One of the consequences of this is that the program will, if it succeeds, lower the rate of consanguineous marriage. Despite the failure by scholars to address this point in literature on the program or similar initiatives, my informants recognized this as a clear, though not explicit, part of the program's goals. Nearly all of my informants did not find any problems with this. However, their relative homogeneity as far as education, geographical location, and social status, as well as the documented prevalence of consanguineous marriages in Jordan, suggests that this is not a universally shared opinion. This indicates the need for a reconsideration of the structure of the Jordanian program, as well as similar initiatives in other countries where consanguinity rates are also high.

Genetic screening programs represent an important opportunity for countries to reduce the burden of certain diseases on their populations. This is especially true for nations in the Eastern Mediterranean region attempting to limit the costs associated with beta-thalassemia. Nondirectiveness has become an integral part of genetic counseling in these initiatives, not least because it distances the programs from the eugenics movement.²⁵⁹ This nondirectiveness is not always in the clients' interest.²⁶⁰ Furthermore, it is unclear whether value neutrality in genetic counseling can be accomplished as part of a public health initiative.²⁶¹ This is because of the clear value judgments present in public health initiatives. Thus, it seems that prevention programs would be better equipped with counselors who were able to provide directive advice for their clients. These counselors

²⁵⁹ Rantanen et al., "What is Ideal Genetic Counselling?," 446.

²⁶⁰ Caplan, "Neutrality is Not Morality," 160 and Fraser, "Genetic Counseling," 650.

²⁶¹ Some may question whether nondirectiveness in counseling is possible at all.

should be trained at an appropriate level. For as the program in Jordan has demonstrated, there are very real concerns of stigma for couples and their families. If public health programs are to employ directive counseling, then they must also aim for the highest level of transparency.

Obliqueness has the possible benefit of avoiding public misconception. However, it is fraught with potential moral pitfalls, let alone the risk of creating future mistrust when the veiled intentions inevitably become public knowledge. This is especially true for genetic screening programs. For a field trying to move on from an unsavory past, it seems like transparency is a better option than nondirectiveness. If, after revealing its goals, dissent occurs, this does not necessarily warrant the canceling of the public health program.²⁶² Nevertheless, it suggests the need for an evaluation of the initiative and its impact, both intended and unintended. It is a mistake to conclude that nondirective counseling will act as a panacea for any unexpected consequences. Furthermore, as the program in Jordan emphasizes, value judgments inherent to public health are not compatible with the ethos of neutrality generally adopted by genetic counselors.

Genetic screening programs should be upfront about their value judgments and become more transparent. This will open the path for criticism from all constituencies, both urban and rural, rich and poor, educated and uneducated.²⁶³ In Jordan, the public may declare that abortion is a more palatable option than preventing consanguineous marriage. Both would serve to lower the number of new cases of individuals affected

²⁶² Kass, "An Ethics Framework," 1781.

²⁶³ This particular breakdown makes sense given the variables that correlate with the incidence of consanguinity. One can imagine other initiatives that would necessitate the involvement of religious, ethnic, and racial minorities.

with beta-thalassemia. This is in line with the duty of public health and representative of the diversity of options that should be explored. Finally, the experience of the prevention program for beta-thalassemia in Jordan also has consequences for bioethicists evaluating future initiatives.

In constructing an ethical framework for genetic counseling, counselors were responding to the tradition of eugenics that was pervasive in the United States and parts of Europe. Jordanians, as well as other Arabs and non-Western populations, have not had the same experience. Thus, they do not necessarily feel the same need to distance directiveness from the counseling process. This may explain part of the difficulty counselors in Jordan have found in conducting non-directive counseling. Bioethicists should be aware of the specific historical context that has shaped their field and understand the limits to its universality. While the scope of this thesis has been limited to questions surrounding directiveness and transparency, there are certainly other issues, such as patient autonomy and access to treatment, that demand a critical reevaluation. There are certain merits, not least academic, to having a far-reaching ethical framework for public health programs. It is also important to be aware of local contexts and where these overarching themes may fall short.

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