"It is Not My Fault": Discrimination in Healthcare

A Reflection of Integration from Refugees in Towns Hadayek El Maadi, Cairo, Egypt

Nyayich Jal Gil



Cover photo: Nyayich Jal Gil in her Cairo neighborhood of Hadayek El Maadi. Photo by author.

About the RIT Project

The Refugees in Towns (RIT) project promotes understanding of the refugee experience in urban settings. Our goal is to understand and promote refugee integration by drawing on the knowledge and perspective of both refugees and locals living in refugee-receiving towns. The RIT Project began in 2017 when the United States—among many other refugee-hosting countries—was undergoing a shift in its refugee policy through travel bans and the suspension of parts of its refugee program. Towns across the U.S. responded in different ways: some resisted national policy changes by declaring themselves "sanctuary cities," while others support travel bans and exclusionary policies. Today, under a new presidential administration and as the COVID pandemic continues to sweep the world, we continue to deepen our understanding of the refugee experience and the ways in which refugees, migrants, and their hosts interact. Our RIT project draws on and gives voice to both refugees and hosts in their experiences with integration around the world.

The RIT project was conceived and is led by Karen Jacobsen. Our management team consists of Fletcher students, and we are based at the Feinstein International Center at Tufts University and funded by the Henry J. Leir Foundation among other donors.

Our goals are twofold

Our first long-term goal is to build a theory of integration from the ground up by compiling a global database of case studies and reports to help us analyze and understand the process of immigrant/refugee integration. These cases provide a range of local insights about the many different factors that enable or obstruct integration, and the ways in which migrants and hosts co-exist, adapt, and struggle in urban spaces. We draw our cases from towns in resettlement countries, transit countries, and countries of first asylum around the world.

Our second more immediate goal is to support community leaders, aid organizations, and local governments in shaping policy, practice, and interventions. We engage policymakers and community leaders through town visits, workshops, conferences, and participatory research that identifies needs in their communities, encourages dialogue on integration, and shares good practices and lessons learned.

For more on RIT

On our website, there are many more case studies and reports from other towns and urban neighborhoods around the world, and we regularly release more reports as our project develops.

www.refugeesintowns.org

About the Author



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Acknowledgments:

I thank the refugees and other immigrants who shared their experiences of chronic disease with me. Some are my neighbors, and some live farther away. I offer my deepest respect to Chan and Thon, who lost their lives to kidney failure while living as refugees in Egypt.

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Introduction

I live in Hadayek El Maadi, Cairo, a neighborhood in the Egyptian capital, to the south of the central city. This is where many refugees live. Most of the refugees in my neighborhood are South Sudanese, as I am, but there are also many Egyptians who live here.

There are tall buildings all around, where you can rent small apartments. It is very, very crowded. When it rains it is muddy, when it is dry the air is very dusty. Most people in the area use the *tuktuk* (a small motorized rickshaw that seats one or two people) for transportation.

In my neighborhood of Hadayek, there is a lot of discrimination, as well as fighting, violence, and abuse. In the street markets, the vendors often increase the price for South Sudanese. Only occasionally if you get the right person, a good person, then refugees can get the same price as Egyptians. The issues of discrimination and abuse are not only an issue in Hadayek El Maadi, but also in other areas of Cairo like Ain Shams, 6th October, Zaytoun, and Harba Unis.

There are many social connections between the refugees in Hadayek El Maadi. If you go out into the streets, you can meet refugees anywhere. There is a church down the street from where I live where many people pray; it is a gathering place for people from South Sudan and Sudan. But when they pray there, they run into problems with local Egyptians. The Egyptians often engage in violence against refugees—they sometimes stone the church and the people. In Hadayek El Maadi, we South Sudanese face so much discrimination, sexual harassment, racism, and abuse. I hear bad words and invasive questions every day. When I went to a shop they told me, "why are there so many of you in this country, you make rent so expensive for Egyptians," because landlords rent apartments to South Sudanese for higher prices than they typically charge Egyptians. The landlords assume that refugees get a lot of money for housing from UNHCR, and there is no monitoring of rents by the government. When refugees are late with their rent payment, the landlord often confiscates their furniture and changes the lock.

I hope that my reflection will express to people in host countries, like Egypt, that being a refugee and having a chronic medical condition is not something that you choose – it is not our fault. In my life in Egypt, I am treated like I am the one who wanted to come here, not the one who was forced to move. Egyptians who have not faced displacement have not felt the pain that refugees feel. Those in host countries should especially understand that refugees facing medical conditions are coping with challenges on top of challenges.

A Note on Terminology

UNHCR Blue Card: This is the <u>Refugee Registration Card</u> that refugees receive once they have been formally recognized as a refugee by UNHCR in Egypt. . It enables them to apply for a residence permit and legalize their status in Egypt, and is valid for three years. When asylum-seekers first arrive, if they do not have documentation, they receive a **white paper**, an "asylum seeker certificate," that proves that they have applied for asylum and their refugee status is pending. If someone applies for refugee status and presents their identification documents, then they are given a **yellow card** that offers protection from deportation and detention, as well as a **residence permit** that is valid for 18 months.

Save the Children: Save the Children is a partner of UNHCR that provides important support for people with chronic diseases, as well as for issues related to child protection. UNHCR sends Save the Children referrals for those who have chronic diseases such as cancer and kidney failure, and Save the Children then connects them to medical care. They also communicate with hospitals and pharmacies to ensure refugees have access to medical services at certain locations.

St. Andrew's Refugee Services (StARS): A refugee services agency that provides education, psychological services, legal aid, and community outreach in Cairo. StARS also offers a Medical Access Program (MAP), which is, as the StARS website explains, "medical counseling and advocacy for accessing medical services, often where no other organization can help." I work in the Psychological Services division of StARS.

A Note on Methodology

This report is based on my own personal experience while working with the Psychological Services Department of St. Andrew's Refugee Services. I describe my interactions with UNHCR, doctors, pharmacies, NGOs, Egyptians, and other refugees in Cairo, including conversations with other refugees that face similar medical problems to mine. When possible, I had face-to-face conversations, but sometimes conversations were on the phone because of the COVID-19 lockdowns. The refugee and immigrant experiences I share are of people who are suffering from chronic diseases. All live in Cairo, some are my neighbors, and some live farther away. I relate to all of these stories on a deeply personal level.

The Author's Position in Cairo

In April of 2014 I fled from my home country of South Sudan. I first moved from the capital city of Juba, and then to Khartoum in Sudan to escape ethnic conflict and civil war in <u>South Sudan</u>. The civil war has claimed thousands of lives, and male children are recruited by force to join the militias.

South Sudanese girls do not have enough opportunities to go to school. In South Sudan, many people believe that when a girl reaches 15 years old, she must get married and become a good housewife. I faced immense challenges in my studies because of the civil war between Sudan and South Sudan. During primary school in Khartoum, there was an attack on my school which was destroyed, and many in my community were displaced. I feel lucky that I managed to earn my diploma.

On October 27, 2014 I arrived in Egypt with my cousin to get treatment after I was diagnosed with kidney failure caused by the chemical weapons and violence I encountered in South Sudan. I underwent several medical examinations with different nephrology specialists and visited three hospitals in Cairo until I was admitted to an intensive care unit for two weeks, as I urgently needed kidney dialysis treatment or a kidney transplant in order to stay alive. However, the cost was very expensive and the chance of a successful kidney transplant surgery was low.



Image: Nyayich in Unmiss Refugee Camp in Tongpang, Juba, South Sudan.

My cousin encouraged me to register with the UNHCR to seek support for the surgery. I filled out a form from the UNHCR office in Six October City and submitted the paperwork. After five months of waiting they called me in for the first interview. However, I did not have time to wait and sought a kidney donor without support from UNHCR.

When I first arrived in Cairo, I went to live in Ain Shams for two months. A cousin helped us get settled in an apartment on Hamed Dis Med Street. Then I moved to El Maadi. After several weeks in and out of hospitals, I was told I needed a kidney transplant. My cousin asked how we could find a donor but the Egyptian doctor said he did not do kidney transplants for non-Egyptians. He got angry at the question and told us it is illegal to buy a kidney from an Egyptian and the government would take legal action against us if we tried. Then he told us to leave his office immediately.

Eventually, with the help of my Uncle Chuol we found a donor from Sudan who came to Cairo for the procedure. The surgery took six hours, followed by weeks of recovery. Since then I have been required to take a host of medications to ensure my body does not reject the transplanted kidney. However, I have difficulty obtaining the medications because of their high cost and the inconsistent supplies and discrimination in some pharmacies. As a kidney transplant patient, I must take anti-rejection medication every single day for the rest of my life or risk significant health consequences including death. The imported medicine is difficult to find in an Egyptian market and when it is in supply it is at a steep price. Recently, there has been a 20% increase in the price of my medicines, and it is now costing more than 4,000 Egyptian Pounds (LE) per month.

My experience has taught me that refugees cannot integrate if they cannot access healthcare, and for those, like me, who are experiencing severe medical issues, no other aspects of integration – work,

social life, or housing – matters until we can access health services. We need a lot of patience, tolerance, self-control, and commitment to healing and living.

City Context

Hadayek El Maadi is a neighborhood of Cairo that lies to the south of the city. It is an area where many refugees are settled, the majority of whom are South Sudanese. As of October 2020, 258,000 refugees and asylum seekers were registered with the United Nations High Commissioner for Refugees (UNHCR) in Egypt, with about 93,000 registered in Cairo (UNHCR 2020).

For more background on migration in the city of Cairo and the state of Egypt, continue to the appendices.



Base map imagery © Google 2021.

Acquiring Medication as a Refugee

In 2018, I visited Mustafa Mahmoud Hospital to receive my monthly medication, however, the nurse at the pharmacy refused service, telling me the medication is provided for Egyptians only and not for refugees or immigrants. I went home without the medication feeling discriminated against simply because I am not from Egypt. As a refugee, I was upset but not surprised that we face racism and discrimination. Accessing medication is difficult because of challenges with transportation, racism, and limited availability of medical supplies.

In November 2019, I traveled downtown to visit a pharmacy called Esaaf. The Egyptian man working at the pharmacy kept me waiting until everyone else in the store was served. After the last customer left, he asked what I needed. I gave him my prescription, but he only looked at me and told me to bring him

a copy of my passport. When I asked him why, he told me it was the law and that he is unable to sell me the medicine without documentation. I left the store feeling unwanted and like I will never be accepted in Egypt. I went to a different pharmacy, which thankfully gave me my prescription without any questions.

Even when pharmacies are willing to serve refugees, it is not easy to get medications because of supply shortages. Once, the NGO, Save the Children, referred me to a pharmacy called Roshdy, with which UNHCR has a contract to provide medicine to refugees with chronic diseases. Refugees can go to any Roshdy branch in Cairo – I go to the nearby one in Maadi. Sometimes the pharmacy doesn't have my medication in stock, and I am told to come back another time. I have tried with three different companies. I tried at another pharmacy and they sometimes will have new supplies the next week if the other pharmacy is out. There is a government run pharmacy very far from me - in 6th October City. Sometimes they call and tell me I will need to go to this pharmacy, but it is a long commute by both bus and metro. Other times they arrange for me to meet someone downtown to pick up the medication for which I am required to pay delivery.

UNHCR Support and Problems

In Cairo, getting access to medical care can be difficult if you do not have a passport. I do not have a passport but rather a type of identification from UNHCR called a Blue Card. I found that the Egyptian medical system does not care about the Blue Card. For instance, back in June 2017 I went to a woman's clinic in Maadi for some tests. The nurse on duty asked for my passport. I showed her my UNHCR Blue Card and she called the clinic manager to ask if the Blue Card was recognized by the government of Egypt. They were worried about the validity of the Blue Cards and asked if I had a personal ID. I told them it was all I had and that government health centers accept the card, recognizing that refugees only pay half the normal fees. We were able to come to an arrangement where I left my contact details and they proceeded with the medical tests, but I had to pay the full price for the tests.

I often find refugees and immigrants in Cairo are suspicious of doctors giving them the wrong medication or over- or under-medicating refugee patients. Refugees are victims of a medical system which does not care about their lives or health. There is no accountability from UNHCR nor the Egyptian government. I have met many patients complaining of being given wrong medications, women who have lost their pregnancy or lives, and many whose situation became worse while being stuck with medical debts. Once, in March 2017, a UNHCR medical doctor told me go to the downtown Rushdy pharmacy to pick up a month's worth of medication. The pharmacist told me that the UNHCR doctor replaced one of my prescriptions, because the older version was expensive and imported from outside Egypt, but that the new medication had the same function and would work without issue. But I was nervous there would be complications, so I refused to take the medication. I left without the medication, but I returned the next day after thinking it through. However, the pharmacist told me they gave my medication to someone else because I had refused to accept it, but also reported to UNHCR medical staff that I had received the medication. This made me feel frustrated and deceived. Eventually, I was able to receive a medical grant from the StARS Medical Assistance Program to buy more of the medicine that I preferred.

Other refugees in Cairo face similar challenges in getting access to medication. One Syrian refugee I work with has a child with a chronic disability, and his family cannot afford the medications he needs.

Another South Sudanese refugee who has been in Cairo for 20 years told me she finds it difficult to get the right medicine for her chronic pain disorder. She is a single mother of two grown children—she supported her children through high school but does not have the money to send them to university. She cannot obtain medicine for herself because it is so expensive, but she also cannot start working because of her health problems. She described feeling depressed all the time about what will happen to her and her children's lives in Egypt. Unlike me, she gets her medicine from a NGO called <u>Caritas</u>. In theory, they provide her medicine monthly, but the reality is that the specific type of medicine that Caritas gives her makes her feel very sick. Caritas said they can't change it to another type of medicine because what they offered her is all they were supplied by UNHCR. Sometimes, she doesn't take their medicine and does what she can to buy her own.

Many refugees I spoke to have lost their medical coverage and treatment because their UNHCR card expired, was lost, or was stolen, and they were unable to speedily reacquire UNHCR documentation. Many refugee patients are not allowed to receive their medications through Save the Children if their cards are invalid or lost—they are supposed to call a hotline. I have tried calling the hotline before and it seems like I had to call a thousands times before getting a response. In 2018, my UNHCR card was stolen along with my purse and all my hospital documents by five Egyptian boys and a Sudanese man. I called the UNHCR hotline to obtain a new Blue Card, but it was impossible to get in touch with the receptionists. I reported the incident to the legal department of my employer, StARS, to inform them that I was attacked and lost all my documents including my Blue Card. After waiting for two weeks I finally received a call for an appointment to acquire a new card. However, I had to provide the police report to validate the robbery. I was able to get the help I needed because of StARS Legal Assistance, but many refugees do not have access to this support. My life, and the life of other refugees in Cairo, would be made easier and simpler if support in acquiring medicine was more consistent.

The Psychological Consequences of Gaps in Support

The money I receive from my job and NGOs is not enough for my rent, food, and other basic expenses, much less for expensive medicine. When I have help from NGOs, I do not have to stress about where I would get my next dose or who I would turn to for money, which gives me relief and allows me to instead focus on my work and my life. But when I do not have access to medicine, the only thing I can think about is my health. The only things I worry about buying are medicine and water—I hardly worry about food. I had two friends with similar kidney problems who died in Egypt on dialysis because they could not find a kidney donor. It was terrible and sad.

One refugee I knew is a widowed, single mother with one young child. She fled from South Sudan a few years ago to look for treatment for her breast cancer. She was able to get two surgeries that she needed in an El Maadi hospital in late 2019. After surgery, she spent six months without any medications because they were too expensive—she could not work because of her health condition, and so she had no income to pay for her medical expenses or to care for her daughter. A bit later, she went for some follow-up tests, and the doctor told her that she *must* keep taking her medications, and that she needed to take these medications for five years after her cancer was removed. But she is not receiving any financial assistance from organizations like Caritas, and is still not able to get her medications. She is very depressed and worried about being able to care for her daughter. Support for school fees from Catholic Relief Services was not enough and her daughter was kicked out of school because she was not able to pay all the school fees.

Sometimes I ask my friends and colleagues at work to lend me a small amount of money to buy a week's worth of medicine. When I receive my salary, I pay back what I have and then continue borrowing as needed. It is what I must do to survive every week. When I borrow money, I only buy one strip of tablets: six strips typically make up the month's supply, and one strip can last me a week, but I do not take a full dosage. Sometimes I get a medical allowance from my workplace: I bring a receipt for the medication I bought and they refund the cost based on the receipt. I also borrow from my churchmates who understand my situation. Back in 2016, I found myself completely out of medicine, and the Save the Children office was closed and relocating and would not be open for three days. I was able to talk to the director at work and they advanced me my salary so I could pay for medication. It was really helpful, and I appreciated that support.

My emotions and my health are connected. If I do not take the medicine, I fear that I am going to lose my kidney and it haunts me constantly. I think about all the effort of my family to help me find a donor and pay for all the medical expenses including the travel to Cairo. My uncle helped raise funds for the procedure and I know it was expensive and difficult for him. I feel like my life has been costly for both him and for me. But I thank God to be alive today. Sometimes I just pray because I do not know who to turn to for help with getting my medication. Sometimes I do not sleep well, other times I get painful headaches. I feel like my world is going to end when I look at an empty strip of tablets. I do not know where to go. I am so exhausted by trying to stay alive. My friends sometimes call to talk about how I am doing. Sometimes people will send me some money from abroad and help. A friend sent me \$100 to help pay for my medication recently. Sometimes cousins and family will help. It depends on my daily needs. I do not care about my food or clothing, just my medicine.

The Added Complications of COVID-19

Finding medication is a constant challenge, but recently with the COVID-19 pandemic I have had to go without it for two months. The pandemic caused all refugee services in Egypt to close, with some health centers and pharmacies remaining open for emergency situations. My Egyptian case worker from Save the Children called me in March and told me that I should not leave my house to pick up medication because my chronic disease puts me at a high risk. They informed me that they would talk to Roshdy Pharmacy to arrange for them to supply me with two months' worth of medication. In the past she had called me about once a month informing me when she had sent my medical documents to the available pharmacy. When I visited their store a week later, the pharmacist told me they had no more kidney medication. I asked when they thought the medicines would be ready next, but they did not know. I left feeling so sad and anxious about what I would do next. I returned home and took out what money I had, about 500 LE, and went to another pharmacy to buy one or two doses.

Conclusion

Refugees all over the world are struggling to access medications and get access to the medical services that they need (Norredam et. al. 2006). Some people die because they are given the wrong medicines; others are not given access to any medicines at all. As a refugee, in Hadayek El Maadi in Cairo I have faced discrimination all around me and my experience has taught me that both refugees and Egyptians need to be patient. Refugees need to be patient when we are interacting with people who are providing us with medical services, because the system is not always under their control. And refugees deserve the patience and tolerance of Egyptians and other hosts everywhere. It was not my

choice to leave my country and live in Hadayek El Maadi, but I accept that I am now here in Egypt, navigating a different system in a country of different people.

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Appendix A: Refugees in Egypt¹

Since the early 1900s, Egypt has hosted numerous communities of refugees and migrants. Armenians fled to Egypt during the 1915 massacre under the Ottoman Empire; thousands of Palestinians arrived in Egypt after the Nakba in 1948 and again after Black September in Jordan 1971; and southern Sudanese refugees started to arrive following the outbreak of the first war in Sudan in 1955. Another wave of Sudanese refugee migration began in 1983 following the establishment of Islamic Law in southern Sudan and the outbreak of the second Sudanese civil war. From the early 1990s, wars and conflict in the Horn of Africa led to large numbers of Sudanese, Ethiopian, Eritrean, and Somali refugees coming to Egypt (Jacobsen, Ayoub, & Johnson, 2012, p. 11). Iraqis began to arrive in Egypt in large numbers following the escalation of violence in Iraq between 2006 and 2007. Most recently, large numbers of Syrian refugees started to arrive in Egypt in 2012. The influx of Syrian refugees significantly altered the makeup of Egypt's refugee population and the structure of the refugee protection regime.

According to UNHCR, as of October 2020, there are 258,882 refugees and asylum seekers registered in Egypt. Fifty-percent of these refugees and asylum seekers are Syrian (130,187), and the other fifty-percent consists of people from Sudan (49,264), South Sudan (19,813), Eritrea (18,995), Ethiopia (16,115) and 52 other countries (24,508) (UNHCR, Oct 2020).

However, these official numbers are questionable.² For example, many "southern Sudanese" registered with UNHCR were recognized as refugees prior to South Sudan's separation from Sudan in July 2012. After South Sudan's independence, many obtained South Sudanese citizenship and identification papers, but they are still listed as Sudanese in UNHCR's database because they did not update their information with UNHCR.

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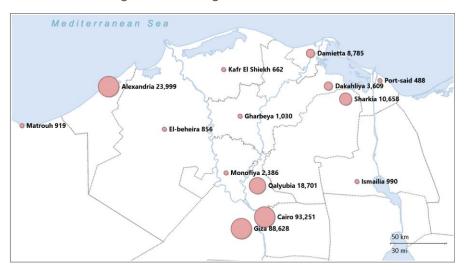
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¹ This section was initially written for the 2018 Refugees in Towns Cairo Report, and was updated with 2020 figures.

² Most official registrations of urban refugee populations are outdated and incomplete, simply because it is difficult to keep track of highly mobile populations.

Appendix B: Refugees in Cairo³

Refugees live in several towns in Egypt, but by far the majority are concentrated in and around Cairo: 36% of all refugees and asylum seekers in Egypt are handled by the UNHCR's Cairo office. The map below shows the distribution of refugees according to UNHCR as of October 2020.



UNHCR, October 2020.

International organizations in Cairo such as IOM, Catholic Relief Services (CRS), CARE, Caritas, and UNHCR divide the refugee population between Syrian and "non-Syrian," often resulting in separate and unequal programming and interventions. Syrians receive the bulk of international assistance, as they do throughout the Middle East, and is manifest in the Syrian Regional Response Plan—which largely ignores non-Syrian refugee populations in all host countries. A prime example is World Food Program assistance in Egypt. In 2016, approximately 30% of registered Syrian refugees received 120-220LE (USD 7-12) per household dependent per month in food vouchers. This can be spent at grocery stores including Carrefour (high end). No other refugee population in Egypt is eligible for this assistance. This inequality has created animosity towards Syrian communities from the "non-Syrian" population.

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³ This section was initially written for the 2018 Refugees in Towns Cairo Report, and was updated with 2020 figures.

⁴ Also, sometimes referred to as Syrian and Africans + Iraqis.

⁵ For more on the "hierarchies of aid" in the Middle East see Davis, R., Taylor, A., Todman, W., & Murphy, E. (2016). Sudanese and Somali Refugees in Jordan: Hierarchies of Aid in Protracted Displacement Crises. Middle East Report, 46(2), 2-10.