Caroline Schiavo
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A Hole in my Heart

(A Creative Nonfiction Memoir)

As soon as I began involvement with No Lost Generation (NLG), I did not realize it would fill a *hole in my heart,* giving me an extended family. Things happen for a reason. Life is not a straight line. So, when I discovered ten-year old, Amil Hassan's experience of illness, *being born in Syria with a hole in his heart,* I wanted to follow him and his family--to reach out because of NLG's advocacy for child protection inside Syria and across the five refugee hosting countries of Turkey, Lebanon, Jordan, Iraq and Egypt ("What We Do").

The story is tragic, filled with a chronic illness and complex emotions. Amil and his family arrive to Chicago via Jordan as unregistered refugees, applying for asylum, vulnerable and challenged with "language barriers, time-limited housing, [seeking] employment counseling, and [hopefully] time-limited health care services" (Maitland 2017, 17). His mother, thirty-seven-year-old Ademar, suffers emotionally. His sister, twelve-year-old, Eliana is malnourished and suffers from post-traumatic stress disorder (PTSD), having witnessed her father, Samuel's death, killed by shrapnel, during a bombing of their hometown, Douma. Their aunt, thirty-five-year-old, Janan is the family spokesperson, the only college-educated one in the family. Through their ordeal of fleeing the war in Syria, Ademar suffers from severe emotional disorder, being distraught over her husband's death and almost neglecting Amil's chronic heart illness. As undocumented refugees, their journey of illness faces significant barriers to healthcare access.

In considering the environment, Bronfenbrenner's framework of circles surrounds itself with layers of relationships, which in Amil's case begins with the inner circle or microsystem, enduring his daily life and struggles when attempting to participate in physical activities typical of his age, due to his chronic heart illness. Beyond this is an outer circle of collaborative people

who are involved in his development, such as his mother, Ademar, his sister, Eliana, and his aunt, Janan, along with the resettlement community he lives in Wilmette, Illinois. The Hassan family is sponsored by RefugeeOne, which "creates opportunity for refugees fleeing war, terror, and persecution to build new lives of safety, dignity, and self-reliance" ("Who We Are"). These relationships are further supported by the mesosystem, with lateral connections to other resettlement families, friends and church through and with RefugeeOne. Then a circle of people exists who are indirectly involved in Amil's development, such as "... health care workers, [doctors], or central school administrators; this is called the exosystem" (Bronfenbrenner 1979, 25). Bronfenbrenner also describes the macrosystem; for Amil's family this involves the societal benefits of the United Nations Commissioner for Refugees (UNHCR) which the Hassan family relied on to help navigate their migration to the United States to obtain refugee status for access to healthcare.

Leaving home was difficult for the Hassan family. "Access to healthcare is one of the biggest concerns for Syria's refugees" (The Lance 2013, 2056). When speaking with Ademar, I asked her, "What are your concerns? Tell me about your past." She reminisced about her hometown of Douma, the family home, the olive and fig trees. She mentions with broken English, "Samuel worked hard for our family and … when he was killed, I didn't know what to do." Her sister, Janan interferes, telling me that, "After Samuel died, Ademar went through feelings of grief, fear, anger, and injustice barely able to take care of Amil and Eliana. The trauma of Samuel's death left her with no feelings and she avoided interaction with the children as they were a constant reminder of their father, her husband. She was suffering emotionally and embarrassed to admit to anyone she needed help." So, I asked, "What happened to Amil? What about Eliana?" Janan reveals that Syrians are, "... less likely to consider conditions chronic in

nature" (Center for Disease Control and Prevention 2016, 5). Syrians do not want to admit that they require help for anything other than physical ailments or symptoms. "That's when I came to help them and realized we needed to flee from Syria as Amil needed serious medical intervention and Eliana was suffering from PTSD with no coping skills." Well, Janan continues, "Once we arrived in Jordan, Amil was given asylum due to his chronic heart illness, which by this time required extensive surgery." But, "despite the current scale and distribution of Syrian refugees, migration is not formally and systematically included as a legitimate component of social determinants of health," and although Amil's condition was legitimate and verified by physicians, we were concerned that the rest of the family would have to soon depart as our refugee status could come under question (Özdemirn 2017, 1). Once in Jordan, we managed to obtain passage to Greece via a smuggler, then to Chicago. It should be noted that, "Between October 2015 and July 2016, more than 7,500 Syrian refugees have been resettled to the United States, with the largest numbers arriving in Texas, California, Michigan and Illinois" (Center for Disease Control and Prevention 2016, 7). Janan tells me, "We felt that we had a chance in Chicago as there was a resettlement community we heard of through others and we hoped to obtain access to healthcare."

Here, Kleinman's Explanatory Meaning of Illness is shown through the emotional stress endured by Ademar brought on by the adversity caused by Samuel's death. Ademar's loss of Samuel crippled her ability to care for her children. She had no treatment available to her as she did not want to admit she was suffering. The cultural significance and meanings of symptoms to her local social group in Douma, was a "tendency to regard such self-evident significance as natural" (Kleinman 1988, 10). Ademar did not realize that her husband's death caused her emotional distress, because in her society, distress is a way of living and the impact of her

husband's death did not have cultural connotation. Everyone suffers in Syria and in transition, "Less attention has been given to the health of refugees who now live outside Syria, particularly in neighbouring developing countries" (Özdemir 2017, 2). Lack and access to healthcare, along with social and cultural stigmas was preventing Ademar from healing. Her "illness was contributing so intimately to the development of [Amil and Eliana's] life that [her] illness was becoming inseparable from [her family's] life history" (Kleinman 1988, 8).

Arriving in Chicago, Illinois came with challenges for the Hassans. The need to find intervention for Amil's chronic heart illness, along with "the bewilderment of encountering a new culture with limited English skills" was almost daunting (McNeely and Morland 2016, 14). As a volunteer for NLG and contacts at RefugeeOne, I met them at O'Hare Airport with a large, "Welcome to Chicago" sign. With an interpreter for the family and Janan's fluent English, we managed to get them to their housing. I went grocery shopping, being careful to inquire as to what groceries they wanted being culturally sensitive, as part of their mesosystem, being compassionate and their extended family, they so desperately needed. Along with refugee resettlement transition, I helped them access others in RefugeeOne to have a volunteer guide them to complete the rigorous healthcare forms with the UNHCR, local health and social services agencies. I explained to Janan, that the forms were important as the first step in getting medical care for Amil. She asked me "How much would surgery cost? How can we afford such surgery with no income, no job?" She begins to cry and with that she translates our conversation to Ademar and all three of us are crying, too. Janan completes all the necessary forms for Medicaid and the Office of Refugee Resettlement (ORR) and waits. Through subsequent conversations, Janan enrolls Amil and Eliana in school. She called to tell me, "Ademar took Amil and Eliana to school and I'm waiting to hear back on our healthcare insurance." Ademar is

working, as a local seamstress and I'm looking for work, as an accountant. I show up later in the week, to help Amil and Eliana with their English homework. Progress is being made. A week later, I receive a call from Janan that they were denied Medicaid because they came to the United States with savings, so that is another barrier to healthcare, denying accessibility to health services for refugees because they saved all of their life to migrate from embattled war. "The right to health is considered one of the main issues pertaining to human rights. The right to health is protected by the Universal Declaration of Human Rights, with Article 25 defining the right to medical care and Article 3, protects the right to life" (Mardin 2017, 2). In the meantime, Eliana's PTSD is keeping her up at night, Amil was sent home from school because he could not participate in physical education and was being bullied, and Ademar stopped cooking for the family, as she was still having emotional difficulty dealing with the loss of her husband. Enough is enough.

The Hassan family's vulnerability is relevant to Engel's Biopsychosocial model, which attributes their illnesses to be viewed with a holistic approach taking into consideration their family history, their illnesses, and their social construct, not merely their medical biological illnesses. They are thrown into a new environment and still grieving for the loss of Samuel, the loss of their home country, the loss of what they thought was a safe environment. According to Engel, "Nothing will change unless or until those who control resources have the wisdom to venture off the beaten path of exclusive reliance on biomedicine as the only approach to health care" (Adler 2009, 611). Medical providers need to take into consideration the whole person, the human side.

I wonder how people survive. At this point, I am visiting the Hassan's only once a week as I am attending the Harris School of Public Policy at the University of Chicago, studying for

final exams. Sitting in their cramped apartment, Janan says, “You know, I spoke to my neighbors and they were denied Medicaid, too, so they filed for Temporary Protected Status, but I’m afraid that will take too long for Amil and every day we wait, is a day closer to his death.” So, that I get this right, “You are still waiting for a reply from the Office of Refugee Resettlement?” Janan replies, “Yes, and since we still do not have official refugee status in the United States we are considered undocumented immigrants, ineligible to buy marketplace health coverage.” Ademar shakes her head as Janan translates for her. A “human-rights based response to refugee healthcare is required for host countries facing similar challenges in their access to healthcare: limitations of medical services, outreach, and political limitations,” along with affordability and health justice (Dadzie 2017, 29). I go home, but I cannot sleep or study, thinking of NLG’s strategy of “mobilizing and engaging communities in the provision of services and addressing barriers” (“What We Do”). The next morning, I awaken emboldened to help the Hassans, so I call some colleagues at NLG and RefugeeOne and we organize a list of NGOs and discover Save the Children. I call up Janan and invite myself over. Once arrived, I tell her there’s an organization, Save the Children, which may be able to help. I gave her all the instructions to call. Janan is energized, especially since she mentioned to me Amil passed out in school today and she had to pick him up early. Before I leave, Janan says, “I finally feel like there’s hope for Amil and once I have a doctor examine him, I’m going to make calls for Eliana, but Amil comes first.” Ademar hugs me goodbye. Janan said, “I will keep in touch.” A few days pass and I receive a call from Janan. “Guess what, Amil has an appointment to see Dr. Hughes, a cardiothoracic surgeon referred to by Save the Children.” I exclaim, “I’m thrilled.” Finally, after months of waiting for refugee status, Amil will have a proper examination and by a specialist. Upon arrival at Dr. Hughes’s office, a physician’s assistant takes Amil’s history with all family members

present, Aunt Janan, the official spokesperson for the family and unofficial caretaker, Amil's mom, Ademar and sister, Eliana too. After the extensive examination, Dr. Hughes asks to speak to Janan and Ademar privately. He kindly says, "Amil requires surgical intervention, as soon as possible, to repair his heart. I need to order many tests, as he has a congenital heart defect and is at significant risk if interventions are not taken." Janan asks, "Doctor Hughes, what are the risks of this surgery? How much will it cost? We don't have health insurance." Dr. Hughes places his hand on Ademar's shoulder, while addressing her and Janan. "Everything will be okay, I am doing what is best for Amil and there will be no cost, as my services are sponsored through Save the Children. The risks of a successful surgery are very high and I regularly perform his operation; I do not envision any complications. If left untreated, his life is in danger. The results of the surgery, after recovery and rehabilitation, will allow Amil to participate in physical activities akin to his peers." I get a phone call from Janan, exclaiming, "Amil is scheduled for surgery next week, Tuesday, the 18th, pending an EKG, MRI, X-Rays and lab work." He'll be at Ann & Robert H. Lurie Children's Hospital of Chicago." I tell her "I'm excited and will place the date in my calendar."

Dr. Hughes's physician patient relationship emitted the Paternalistic Model. He displayed care, sympathy, and empathy, acting as Amil's "guardian, articulating and implementing what is best for the patient" (Emanuel and Emanuel 1992, 2221). He also used the Informative Model in explaining the critical need for surgical intervention and the beneficial results, as "the purveyor of technical expertise, providing the patient … truthful information" (Ibid). The role of the physician in providing factual information and acting as a guardian is a welcome approach, easily accepted and endorsed by Amil's family as refugees, still undergoing transition.

On Tuesday, April 18th, I met up with Amil's family before he is brought in for surgery. I turn to Amil, give him a "high-five" and tell him, "You've got this." He smiles and is whisked off to the four-hour cardiac surgery. With Amil in surgery, I inquire of Janan, "So now you need to concentrate on getting Eliana intervention for her PTSD and Ademar an appointment to see a psychologist for her emotional distress." Ademar, whose name means "strength" in Arabic embraces me and says "As-Salaam-Alaikum" (May the peace be with you). You know, she tells me "'Amil's name in Arabic means "hope"; my name, Janan, means "heart and soul" and Eliana's name symbolizes, "the daughter of sun." So, "everything has to turn out right for us, it is in the stars -- with Amil's surgery destined to be successful and soon our refugee status will be approved." You are a savior--if you did not come into our life, I don't know what we would do or how we would navigate this whole healthcare access debacle." They called Ademar's name; Amil was out of surgery. The stars were in line.

Unfortunately, delays to chronic illness of refugees are encountered on a daily basis in the United States and refugee host cities. "Each year, a small number of nations make a commitment to accept a certain amount of refugees" (Maitland 16). Knowing this increase is substantial, it needs to be accompanied by assistance in navigating new healthcare systems, along with culturally appropriate counseling. Access to healthcare for refugees is challenging with language barriers, discrimination, different customs and norms and navigating a complex healthcare system. "In response to these direct challenges, health policies should be aimed at improving availability, … accessibility, where refugees can physically and economically access healthcare without facing discrimination and lack of information: acceptability, where healthcare personnel respond appropriately to refugees' health needs while considering culture, and

accountability, where entities are transparent about healthcare strategies set in place for all family members" (Dadzie 2017, 29-30).

Checking into with the Hassan's a few days after Amil was discharged, I was told by Janan, "Amil's doing fine and with the help of Save the Children, I was able to make an appointment for Eliana and Ademar." Millions of refugees are departing Syria and the world needs to have solutions when they arrive to access healthcare in host countries and the United States. Perhaps, all stakeholders need to form partnerships to consider socializing healthcare. In the meantime, with social frameworks and models in place for healthcare professionals, the physician-client relationship should focus on the individual and family cultural history, in addition to their medical history. With awareness and continued professional education, physicians and healthcare professionals should provide compassionate care taking into consideration the holistic needs of the patient, where healthcare for refugees is easily available and attainable worldwide.

(Note: Character names, except mine have been fictionalized, but agencies mentioned are real.)