European School of Oncology
Learning to care

Cancerworld

click here to receive your free copy by post

Editor
Alberto Costa

Senior Associate Editor
Anna Wagstaff

Associate Editor (Online)
Daniela Ovadia

The silent cancer refugees crisis

MOHAMMED YAHIA

14 February 2018 CancerWorld Plus 0

NUMBER 1 PLUS

Relief efforts aim at primary care, leaving refugees and displaced people with cancer without treatments or psychological support. In a worsening scenario, doctors are daily confronted with the hard choice between using the scarce resources to offer basic care

to many or saving a single life

When one-year-old Farah and her parents fled from Syria to Lebanon, she had already been diagnosed back home with neuroblastoma. In Beirut, with support of one of the local aid NGOs, Farah was put on chemotherapy that cured her tumor.

However, she relapsed soon after and the tumor came back more aggressive. Try as hard as they could, the NGO that was helping them ran out of funds for her treatment. That's when her parents decided to make the perilous journey back to Syria, hoping she would at least receive the treatment she needed to stay alive there.

Shortly after going back, however, Farah passed away.

The world is no stranger to refugees. People have had to flee their homes due to wars or in fear of prosecution since forever. When nations came together after World War II and created the United Nations, agencies that focus exclusively on the needs of refugees were set up, and they have become increasingly better at having to deal with refugees over the years.

© United Nations

However, the last few years have seen a shift in the type of refugees, and thus in the challenges facing aid workers and volunteers. In the past, most refugees were from poor and less developed countries, and their healthcare needs were mainly for communicable diseases like cholera or Ebola, or maternal diseases. But the Arab Spring has led to thousands of people from middle-

income countries, such as Syria, having to flee their homes, and these come with different healthcare needs. According to UNHCR, the UN Refugee Agency, over 5.6 million Syrians have fled their country since 2011, and over 6.1 million have been internally displaced.

Rather than the easier to treat communicable diseases that aid workers were dealing with, they now faced non-communicable diseases such as diabetes or cancer, which are much more expensive to treat and require a very different skill set and expertise.

“Cancer treatment is very expensive. The treatment of one kid may cost up to 100,000 USD in some cases,” says Layal Issa, a paediatric oncologist working in Beirut and president of Karma Association, a Lebanon-based NGO supporting Syrian children refugees with cancer, and who supported Farah’s treatment. “The duration of treatment is also long, ranging from six months to three years, depending on the diagnosis. So children [refugees] with cancer are abandoned, as if they do not have the right for treatment.”

Strained healthcare systems

While nearly one million refugees from Syria have found their way to Europe, the largest numbers of refugees have fled to neighbouring countries. Turkey has received nearly 3.5 million refugees, while Lebanon, a small country with a population of around six million people, has received more refugees than all of Europe combined. This has stressed the healthcare systems in these countries far beyond its capacity. In Lebanon, the Ministry of Public Health usually cannot afford treatments for the large number of refugees, so the patients are left to pay for their expensive treatments.

“The ministry does not have a budget to treat non-Lebanese patients, we already can hardly make ends meet and we always have around 20% deficit in the public hospitals’ budgets at the end of the year,” says Waleed Ammar, the general manager of the Ministry of Public Health in Lebanon. “In Lebanon we now have 1.5 million refugees. No country can bear such a load alone; we need international aid for an international crisis.”

POPULAR

Hello, my name is Kate Granger

Highlight, Profile 21 June 2016 7

The invisible cure. Should we be talking more about cancer surgery?

Cover Story, Featured 12 September 2016 5

Woman and baby at the infirmary of the Nizip refugee container shelter (Turkey), in 2016. © European Union 2016 – European Parliament (creativecommons.org/licenses/by-nc-nd/4.0/)

That aid, however, has been decreasing. The Regional Refugee and Resilience Plan (3RP), which was launched to support Syrian refugees in neighbouring countries, only received 63% of its 4.54 billion USD requested budget in 2016. An expected decrease of UN funding from the United States could make it even harder for UNHCR to provide expensive healthcare to refugees.

"The problem is not with the doctors, but with the healthcare system. In Lebanon, there are limited hospitals that offer treatment for children with cancer. The hospitals are well equipped, but the patients have no financial coverage most of the time," adds Issa. Karma Association treats children refugees with cancer in two hospitals in Lebanon, and one of these has already

Is first-in-human clinical research always ethical?

Featured, News 4 February 2017 5

TAG CLOUD

BEST CANCER REPORTER AWARD

BREAST CANCER

CANCER CANCER DRUGS

CANCER RESEARCH CANCER SERVICES

CARE CHEMOTHERAPY

CHILDHOOD CANCER CLINICAL RESEARCH

CLINICAL TRIALS

COLORECTAL CANCER

COMMUNICATION DEVELOPING COUNTRIES

DRUGS ESMO ESO

HEAD AND NECK CANCER LUNG CANCER

stopped accepting patients from the NGO because they have not paid their debts. “So these kids are currently with no treatment, and they can do nothing about it.”

The UNHCR, the UN aid agency, provides healthcare for registered refugees at a cost of 1000-2000 USD annually. However, cancer care and medication is normally far more expensive than that. In these cases, the decision falls to the UNHCR’s Exceptional Care Committees (ECCs). These are formed from a UNHCR medical doctor and several local physicians, and they determine the eligibility of a refugee for treatment above the normal cost. The ECCs have several criteria for taking this hard decision, such as necessity and feasibility of the treatment, as well as disease prognosis.

In most of these countries, there are no cancer surveillance programmes or national registers for the number of cancer patients, let alone refugees with cancer. This makes it impossible to calculate the actual burden. However, according to a study published in *The Lancet Oncology*, the ECC in Jordan received 511 applications for cancer treatment between 2010 and 2012 for refugees. But only 246 were approved – less than half of those that applied. None of them were refused because the diagnosis was wrong, but the major reason was that prognosis of the disease was deemed ‘bad’.

“It is extremely hard to be a doctor in that setting,” says Shadi Mahmoud, a general surgeon from Egypt who volunteered in refugee camps in Greece and South Sudan. “To say ‘I cannot do it’ is very hard, and can take a toll on the doctor.” He explains that this is usually a joint decision between the doctors based on the realities of their resources, but that does not make it any easier.

There are several private hospitals in Lebanon, and they have the capacity to help some of the refugees, but most of them have fled their countries with little to no money, and often have no chance of finding a job to pay for their treatments. The UNHCR and other aid organizations struggle to find funding to pay for these treatments. With the decreasing funding they are receiving, however, they must make harder decisions on whether to use the money to treat

MEDIA
MELANOMA
MRI
OVARIAN CANCER
PALLIATIVE CARE
PANCREATIC CANCER
PERSONALISED MEDICINE
PREVENTION
PROSTATE CANCER
QUALITY OF LIFE
RADIOTHERAPY
RARE CANCERS
RESEARCH
SCREENING
SIDE-EFFECTS
SURGERY
SURVIVAL
TARGETED THERAPIES
TREATMENT
UICC
WORLD ONCOLOGY FORUM

RECENT COMMENTS

ROGER WILSON ON Let’s be honest: our research efforts centre on drugs not patients

GIUSEPPE ON Let’s be honest: our research efforts centre on drugs not patients

STORME GUY ON Let’s be honest: our research efforts centre on drugs not patients

hundreds in need of basic primary healthcare or spend it to save one life. If these patients then do not find a private donor or an NGO to support them, they will most probably die from the disease.

“There is much that wealthier Arab states can do to help,” says Ammar. “If they contribute more, they can help ease the burden especially in humanitarian cases.”

For Issa, finding private donors for Karma’s work with children with cancer is becoming harder because most funders do not see this as an emergency, and would rather donate to primary healthcare. “I think it’s not fair, I always put myself in these kids’ shoes before trying to decide. Everyone has the right for treatment; it’s their basic human rights.”

Camps in need

Mahmoud volunteered in a refugee camp on the island of Lesbos, Greece, in 2016. He was the only doctor on camp, which was far from equipped to deal with refugees with tumors. Everything they had was rudimentary – mainly to treat simple infections or first aid. “We had networks connecting the different camps, and every once in a while we would get calls from someone looking for connections to transfer someone with a special need to a proper hospital, but it was extremely hard,” he adds.

“The camps are in no way equipped to deal with cancer cases. Some camps were lucky to have one or two volunteers with medical training. Others had little to offer,” says Mohamed El Dahshan, a volunteer at one of the camps in Lesbos that is a first stop for refugees fleeing on boats in the Mediterranean Sea.

“The only thing that they are able to do is to use painkillers to reduce the pain and suffering from cancer. There are psychologists in some of the bigger camps, which would be important to help cancer patients, but most camps rarely had any,” adds Mahmoud.

General view of the Osmaniye Cevdetiye Camp, in Turkey, during a visit by a delegation of the European Parliament in 2016. © European Union 2016 – European Parliament (creativecommons.org/licenses/by-nc-nd/4.0/)

Language can also be a serious barrier for communication. While the refugees can manage to ask for food, shelter or extra dry clothes with sign language, it becomes much harder to explain symptoms or ailments this way. If they needed to be taken to a hospital, they had to be accompanied by someone who knew English and Arabic to act as a translator for the doctors too. Offering psychological support is also hard across languages.

When he spent three months in a Médecins Sans Frontières (MSF) hospital in Agok, South Sudan, Mahmoud could help more people and offer some basic surgeries, but was still limited by the resources that the hospital was able to scrap together. “If we knew that a patient had cancer, we would not operate on them because we knew we wouldn’t be able to support them. We would

refer them to one of the bigger hospital in Sudan instead," he explains.

In one case, he received a patient with an advanced tumor in the esophagus and the hospital did not have the resources to help her. Her family could not afford to pay to transfer her to Sudan either. "We had to explain to her and her family that we couldn't do anything except relieve the pain as best as we could. These things are hard to forget."

Easing the psychological pain

The size and extent of the refugees crisis has caused Michael Silbermann, the executive director of the Middle East Cancer Consortium (MECC), to organize a workshop last year in Sicily, Italy, that brings stakeholders together to look for real solutions.

Drawings by guests of the Nizip refugee container shelter (Turkey), in 2016. © European Union 2016 – European Parliament (creativecommons.org/licenses/by-nc-nd/4.0/)

One of the most important take away messages from the workshop was the need to build up palliative care capabilities in the host countries that focuses on the needs of refugees and migrants in particular. "We see the suffering of cancer patients, especially when they reach the terminal state. We cannot

ignore that," explains Silbermann.

In 2019, the MECC will host an expanded workshop that will focus on providing courses in palliative care and will have participants from migrant countries along with other Middle Eastern states that host refugees on their journeys. The workshop will give focus primarily on the psychological aspects.

To deal with the thousands of refugees that come to its shores daily, Sicily has created teams that include physicians, psychologists, social workers and cultural mediators – these are people from the same countries as the refugees who understand the culture and language.

"Undoubtedly, the number one problem is the psychological one," explains Silbermann. "The refugees have just made this long and horrible journey. Now they have a place to stay, but they feel that they are aliens, they feel they don't belong. Add to that that they don't know the language, and that puts them under tremendous psychological pressure. So it was really good how the Italians put really professional psychologists into the teams."

He adds that nurses in the Middle East have taken over the humanitarian aspect of the treatment provided to cancer patients and their caretakers. By forming much closer contact with them, they are able to help where chemotherapy or radiotherapy may not. "They of course do not prescribe medicine, but they talk to them, and that is a powerful approach," says Silbermann.

Nermeen Youssef, a refugee support volunteer who helped with the settlement of Syrian newcomers in Edmonton and now works as a health policy advisor, agrees that psychological support is the place to start. Much of that can be provided by aid workers in refugee camps, who are the first point of contact for those who have made the long and uncertain journey from their homes. "Aid workers can provide basic psychological support to the patient and to the family by providing a positive and compassionate atmosphere during their direct interaction, but often

the patient needs to be directed afterward to get professional help."

She also adds that aid workers should support health professionals as they help the families and caregivers of cancer patients navigate the healthcare system of the new countries they settle in, which can be quite challenging to them.

Issa, the president of Karma Association, argues that the global approach to funding refugee healthcare needs to be revised. Smaller NGOs, like the one she runs, cannot handle the large influx of cancer patients and major aids organizations, such as UNHCR, should be empowered to help. "Cancer should be included on the list of diseases that are financially covered. It is so wrong to take away a patient's right for treatment because it is very expensive."

"What the refugees really need is spiritual support and emotional support; this is what bothers them the most. That is the direct link between treating cancer patients and treating refugees," says Silbermann. "It is easy to drive drugs into your veins, but a harder option but not less efficient is to address the patient's personality. Treat them as human beings, not as refugees."

A safe corridor for drugs and health supplies

While the world usually focuses on Syrian refugees, the majority of those who had to flee their homes have actually been displaced within their own country. This often complicates their access to healthcare, especially when they are stuck in areas that are constantly under siege, preventing aid agencies from reaching them.

Wissam Mohammed, a medical oncologist who is currently the director of the Dar al-Rahma Medical Centre in the Eastern Al-Ghouta area of rural Damascus, struggles daily to get her patients the chemotherapy treatments they need to survive. By the end of January

2018, the hospital had 620 patients in need of treatment and few drug supplies to help them. The waiting list can be long, and 38 patients have died waiting for their turn.

Women and baby at the infirmary of the Nizip refugee container shelter, during a visit by a delegation of the European Parliament in 2016. © European Union 2016 – European Parliament (creativecommons.org/licenses/by-nc-nd/4.0/)

"Al-Ghouta is under heavy bombardment so the patients are always moving to look for safety, making their access to medication unstable," she says. "The fear and the psychological deterioration, as well as poor access to healthy food, worsens their conditions further." Most have also lost their jobs so cannot even pay for basic foodstuff.

Syria had one of the most advanced healthcare systems in the Middle East before the civil war, but now, most doctors and nurses across Syria have had to flee the country. Those who stayed work overtime to try to secure affordable medication to all cancer patients who need it. However, the tight siege since early 2017 caused them to run out of medication and they struggle to get more from outside the country.

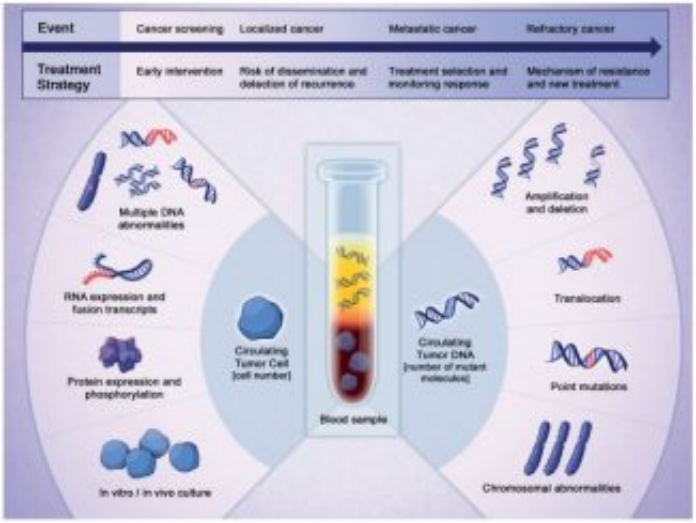
"We really need a safe corridor to allow medication in, and to allow the most severe cases out of the country where they can receive proper treatment. Nearly 80% of our patients are women and children who are torn between cancer and the fighting on the ground.

> *Treatment is their most basic human right," adds Wissam.*

AID ARAB SPRING CANCER DRUGS MIDDLE EAST REFUGEES RELIEF SAFE CORRIDOR SUPPLIES SYRIA UNITED NATIONS

PREVIOUS ARTICLE

RELATED ARTICLES



What can we learn from liquid biopsies?