Breast cancer in Venezuela: back to the 20th century

Facing scarcity of medicines and broken-down medical equipment, women diagnosed with breast cancer in Venezuela resort to more radical means of treatment. Hildegard Willer reports.

When she realised that she could not continue to afford the therapy that would save her life, Dennis Mercado felt desperate. Aged 48 years, Mercado had been diagnosed with breast cancer 3 years before. As part of her post-surgical treatment, she had been taking the hormonal blocker goserelin for several years, costing about US$100 per month. As an internal medicine specialist, Mercado urges her patients to do everything they can to complete their treatment; a non-completed treatment scheme, Mercado says, can be useless. But as a patient, she could not afford to do so. Mercado only makes about $20 a month.

"My hormone level was rising, and I knew that there was no other option than to do another surgery", she said. In April, 2018, Mercado had an oophorectomy to remove both her ovaries, the most radical solution to stop hormone production.

Being diagnosed with breast cancer is a shock for any woman, but if that woman lives in Venezuela today, it means an endless struggle to obtain and pay for treatment. Often, it can mean losing both breasts and ovaries, even though alternative treatments have been proven to be more effective.

"Mastectomies in our hospital have risen by 30–40% in the past 5 years", says Gabriel Romero, head of the breast cancer unit at the Luis Razetti Cancer Hospital in Caracas. He says that oophorectomies are also on the rise in his hospital, and possibly in the whole country, although there are no data available to confirm this at the time.

Doing radical surgery to treat breast cancer might have been standard practice 30 years ago, says the 66-year-old surgeon, but nowadays, breast cancer is treated by pre-surgical or post-surgical chemotherapy, radiology, and, in case of a hormone-driven cancer, a hormonal treatment. These complementary treatments allow surgeons to preserve the breast in most cases.

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But in Venezuela, these treatments are no longer available in public hospitals. The country's health system has been deteriorating for the past 20 years; maternal mortality, for instance, has increased by 30% since 1998, according to Marino Gónzalez, chair of public health at Simón Bolivar University and member of the Venezuelan Medical Academy.

The decline of the Venezuelan health sector accelerated in 2014, when the recession started. "This recession is the worst one Latin America has ever been in, and is among the worst recessions worldwide", says Gónzalez. The country's hyperinflation, which has been rising since November, 2017, is set to hit a record level, with the International Monetary Fund saying in July that hyperinflation could reach an annualised rate of 1 million % by the year's end, setting Venezuela within the countries with the worst inflation rates in history. "The public health system in Venezuela is at its worst at the moment, and it will become worse as hyperinflation continues", says Gónzalez.

Broken public services

In his hospital "we only had two radiotherapy units, but these were damaged years ago", says Romero. The unavailability of radiotherapy is the case not only at the Luis Razetti hospital, which is the national public hospital for patients with cancer, but throughout Venezuela, he says. According to him, patients wait for more than a year to get radiotherapy and relapses and deaths have increased.

Diagnostic facilities are also scarce—there are few functioning mammography screening units in the country and doing immunohistochemistry is complicated by the inadequate supply of slides and reagents. Romero's list of what is missing in the Luis Razetti hospital is seemingly endless—cancer drugs, surgical instruments, syringes, gloves, palliative drugs, and reagents are all unavailable. "At the moment we can only do four surgeries a week, because we have no material", says Romero. "A patient diagnosed [in July] will be on my operation list in December."

In these circumstances, many doctors, medical technicians, and nurses have chosen to leave the country. "The doctors who have stayed are busy getting the paperwork done to leave", says Romero. "What is most important is that we maintain our capacity to train our oncology students."

Therefore, breast cancer is being diagnosed late. "Last year, 65% of the cases I saw were locally advanced cancer,

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Health workers seen protesting in Caracas, Venezuela, on July 30

whereas in 2010, only 38% of the patients came with advanced cancer", says Romero. "In medicine in Venezuela, we are going back to the beginning of the 20th century."

Unaffordable private services

In 2009, breast cancer surpassed cervical cancer as the most important cause of cancer mortality among women in Venezuela, and is the fifth highest cause of mortality among Venezuelan women altogether, according to Luis Capote Negrín, cancer epidemiologist and head of the Venezuelan cancer register. Although in many countries, breast cancer incidence has risen—due in part to improvements in early detection—mortality of patients with breast cancer has remained stable, thanks to better treatments. Venezuela's breast cancer records, however, show a slight but continuing increase in mortality, said Capote.

In Venezuela, doing radical surgery is now often the only option to increase a woman's chances to recover from breast cancer. Jorge Uribe, director of the private Clínica de Mamas in Barquisimeto does two or three breast cancer surgeries a week in his clinic. "Women ask me to remove a breast because they cannot afford chemotherapy and radiology", says 73-year-old Uribe. Unlike the public hospitals, Uribe's clinic has functioning radiotherapy equipment, but treatment can average hundreds to thousands of US dollars, although the average Venezuelan salary is now just a few dollars a month. "It goes against everything I have learned about breast surgery, but radical mastectomy is the only way to increase women's chances of recovery if they cannot afford the radiotherapy", says Uribe.

Fighting for access to care

In 2015, Mildred Varela was in her second week of radiotherapy treatment when she was told that the radiotherapy device in her hospital had broken. She and other patients chained themselves to a fence in front of the Presidential Palace in Miraflores to protest against unavailability of radiotherapy treatment. This gave birth to the Conquistando la Vida civil association (Aconvida), a group of about 70 members—most of whom are patients with breast cancer—which organises medicine donations, offers group therapy, and organises political action.

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Aconvida is one of several patients' organisation that have emerged from Venezuela's health emergency. It is part of Codevida (Coalición de Organizaciones por el Derecho a la Salud), and emphasises the human right of access to care. "It is important for us to struggle and fight for our rights. We do not want to inspire pity", says Varela. Patients' organisations, non-governmental organisations, and foundations now have a central role in supplying medicine and money for treatments.

As a patient, Mercado feels strangled in her efforts to get treatment, she says. She received no medication from April onwards from the so-called High Cost Pharmacy, the social security institution that should provide free medication for patients with chronic diseases such as cancer. As part of her therapy post-oophorectomy, Mercado has to take tamoxifen, a generic daily hormonal blocker, which is part of the WHO List of Essential Medicine and costs about $20 per month. In Venezuela nowadays, tamoxifen is not available.

"I have to organise for somebody to bring two or three boxes of tamoxifen from Colombia or Ecuador. Sometimes my sister makes a 600 km trip from Barquisimeto to Cucutá, Colombia, only to get me tamoxifen."

Varela was also prescribed tamoxifen after her mastectomy 4 years ago. She is currently enjoying short-lived relief from her endless struggle to get medicine as someone recently brought her three boxes of the drug. She still feels the consequences of the surgery, and wears an elasticated sleeve to prevent swelling in her arms due to lymphoedema, a common complication. "Fortunately I was given the sleeve as a gift from abroad, because, in Venezuela, you cannot get it", says Varela.

The battle to get medication and therapy is compounded by the faltering infrastructure for access to electricity, water, and transport. "At the moment, we only have access to water for 20 minutes a day", says Mercado. After 2 weeks without water, Mercado's neighbours have been getting together to buy water from private providers.

Varela has still some hope that the Pan American Health Organization (PAHO) might be able to improve the drug supply for Venezuelan patients. In her last visit to Venezuela in June, 2018, PAHO Director Carissa F Etienne met with the president of Venezuela, Nicolás Maduro, health officials, and civil society groups, and declared that PAHO would lobby in the region to get funding for medication. Antiretroviral drugs for the treatment of HIV were, in July, brought to Venezuela by PAHO's strategic fund but, to date, there is no visibility on when cancer treatments might be delivered with the same scheme.

In a plea to mitigate his anger towards the excessive amount of mastectomies that he has had to perform, Uribe says he will write a letter to the First Lady of Venezuela to inform her of the situation. For his part, Romero shakes his head, as if incredulous at the state of his hospital, which would have been unimaginable to any Venezuelan doctor only a few years ago. When asked what needs to happen to remedy this situation, Romero answers "esto debe pasar"—this must pass.

Hildegard Willer