Jackline Nyirarukundo sits alone in her modest one-room house in Mwibiza Cell, Kagarama Sector, Kayonza District. The small room is simply furnished, with a mattress on the floor and a bench for visitors. Clothes hang neatly on the wall, adding a personal touch to the otherwise sparse space.

Born in 1975, Nyirarukundo never married and is childless, she leads a solitary life as she suffers from elephantiasis.

“It’s been 26 years since I contracted this disease, locally known as ‘Imidido’—elephantiasis,” she recalls with a lighthearted tone. “At first, people thought it was genetic, and I even asked my relatives if it ran in our family.” Many in her neighborhood, including those close to her, mocked her legs, which were swollen, disfigured with asymmetry, skin discoloration, and nodular growths on her toes and feet.

“At one point, I thought I was bewitched,” she says, frustration creeping into her voice.

It wasn’t until she visited Gahini Medical Hospital that she received a diagnosis. A South African doctor named William examined her and said, “You are suffering from elephantiasis, due to untreated infection for lymphatic Filariasis.”

The stigma surrounding elephantiasis has been one of the hardest challenges for people like Nyirarukundo. The misconception is that the disease is caused by witchcraft or divine punishment isolates sufferers.

“At first, they isolated me, thinking the disease was contagious,” she recalls. Dr. William prescribed foot washing, wound care, and medication, but after his departure in 2004, there was no follow-up. “The church covered my medication, costing over Rwf 60,000, but could no longer continue. Even with health insurance, I couldn’t afford it,” she explains.

Rukundo, a 48-year-old livestock farmer from Nyagitabire cell, Rugarama Sector in Kayonza District, once proud of his strength, now struggles. He recalls, “My right leg started swelling in 2001. Over time, the itching grew worse, followed by ballooning because of fluids, and even basic tasks like tending to my livestock became impossible. As the disease progressed, the skin and underlying tissues thickened, causing swelling and damage over time,” Like Jackline, Rukundo suffers from elephantiasis, a Neglected Tropical Disease (NTD) that often affects farmers. Mudaherana Jean Claude, also from Kayonza District, has suffered from the disease since he was eight.

“At one point, my parents thought I had been bewitched and took me to a traditional healer, but nothing worked,” says the 30-year-old Mudaherana.

Rukundo reflects on his isolation: “People turn away when they see me. They whisper behind my back. I wonder if I will ever truly be accepted.” His words, tinged with quiet strength, reveal the toll of stigma.

Medical Context

The causes of elephantiasis are Lymphatic Filariasis (LF) and Podoconiosis (Podo) parasites. LF is an infection spread by mosquito bits, where worms block lymph vessels, causing swelling, especially in the legs. In Rwanda, it is common in areas like Kayonza, Nyamasheke, and Rusizi. It can lead to severe complications, including recurrent infections, ulcers, and permanent disability if untreated. Experts note that LF affects all age groups, with infection often starting in childhood.

Graphical pressentation of Lymphatic Filariasis, a type of Elephantiasis from an infection spread by mosquito bites, where worms block lymph vessels, causing swelling, especially in the legs. (Source: WHO)

On the other hand, Podo is caused by exposure to irritant minerals in volcanic soils, especially walking barefoot in areas like Musanze, Rubavu, and Nyamasheke District in Rwanda, increases the risk, affecting rural farming communities.

In Rwanda, where infection of LF was considered high by the WHO and the Global Alliance to Eliminate Lymphatic Filariasis (GAELF), there was no reliable data on distribution and prevalence of LF.

Aimee Mukansenga, a community health worker, explains, “Farmers are the most affected with elephantiasis. Many believe they are cursed and turn to witch doctors instead of seeking medical treatment.”

As of 2018, 51 million people were infected with Lymphatic Filariasis (Elephantiais0—a 74% decrease since the launch of WHO’s Global Programme to

Eliminate Lymphatic Filariasis in 2000. The Rwanda Biomedical Center (RBC) reports around 6,000 new cases annually.

Stigma and Misconceptions

The stigma surrounding elephantiasis has been one of the hardest challenges for people like Nyirarukundo and Rukundo (not family related). The misconception that the disease is caused by witchcraft or divine punishment isolates sufferers from their communities.

A 2020 survey by the University of Global Health Equity revealed significant gaps in knowledge among Rwandan healthcare providers regarding the disease, with 76% holding negative views toward those affected.

Mukansenga observes these economic challenges firsthand: “When people can’t work, the entire community suffers. The cycle of poverty deepens, and recovery becomes harder.” Farmers affected by the elephantiasis are often unable to tend their crops or livestock, impacting their families and the local economy.

Personal Stories of Loss

Nyirarukundo abandoned her dream of running a market stall because her condition prevents her from walking or standing for long. “I wanted to sell vegetables and fruits, but my legs won’t allow it,” she says.

Rukundo, once a cattle herder, now relies on his family for tasks he can no longer perform. “I’ve lost my income and independence, leaving my family to bear the burden,” he admits. “There are nights when I lie awake, thinking about how different my life could have been without this disease,” he says with quiet sorrow.

Government and NGO Initiatives

Rwanda has set a strategic plan, aligned with Vision 2050 and the SDGs, aiming to eliminate elephantiasis by 2030 with WHO support. Key interventions include chemotherapy, vector control, surveillance, and improved sanitation.

Dr. Eugene Ruberanziza stresses that continued education and support are essential. “In Rwanda, agricultural activities are a major risk factor for elephantiasis,” he explains.

Dr. Jules Mugabo Semahore, Head of Neglected Tropical Diseases (NTDs) at WHO Rwanda, is optimistic: “We support the Ministry of Health and RBC in their mission to eradicate elephantiasis by 2030.”

WHO, in partnership with the Global Alliance to Eliminate Lymphatic Filariasis (GAELF) have been pivotal in addressing this issue globally, Since the launch of the Global Programme to Eliminate Lymphatic Filariasis in 2000, there has been a 74% reduction in the number of infections worldwide.

Rwanda is making significant progress against elephantiasis through a multi-sector approach. With support from partners like WHO, The End Fund, Merck KGaA, WFP, and HASA, the government is improving treatment and raising community awareness. Elephantiasis control is part of Rwanda’s broader strategy to reduce neglected tropical diseases (NTDs) by 2030, aligned with the Sustainable Development Goals (SDGs).

RBC, in collaboration with WHO, has rolled out an extensive National NTD Strategic Plan. This plan focuses on key interventions such as early diagnosis, regular foot care, wound management, and community education.

Heart and Sole Africa (HASA), a non-governmental organisation that works with RBC and 11 health clinic partners’, says it has 7,000 registered patients suffering from elephantiasis in Rwanda.

For instance, at St. Vincent Children and Family Centre in Musanze District, HASA provides foot baths, skin, and wound care, compression therapy, and organizes regular group sessions.

Jeanne Uwuzeyimana, the HASA Director and Representative in Rwanda, explains that they provide essential treatments for patients, including foot soaks to keep the wounds clean, scrubbing, and applying medications such as antiseptics and antifungals. These treatments help eliminate bacteria, reduce odor, prevent flies, and alleviate pain.

Jeanne Uwizeyimana HASA Director and Representative in Rwanda

She explains that under compression therapy, they use specially designed elastic bandages, compression garments, or wraps to gently and consistently compress swollen limbs. “This helps drain waste, toxins, and excess fluid, reducing lymphedema, swelling, and discomfort. It also enhances mobility, enabling patients to continue farming, and other daily activities while lowering the risk of skin infections.”

“The therapy improves fluid circulation, relieves pain, and allows patients to wear the garments comfortably afterward. This supports their ability to return to work and care for their families.” She observes.

During group sessions, both new and returning patients from various locations come together to share experiences, discuss personal challenges, provide testimonies, and receive counseling. These sessions aim to ease the mental health burden and reduce stigma. “The sessions play a vital role in helping patients combat stigma and regain confidence,” she explained.

Additionally, HASA trains medical professionals and community health workers (CWHs) and conducts community outreach and awareness campaigns to educate and support affected individuals. “We have representatives in various clinics who are trained to provide counseling and treatment to patients,” said Uwuzeyimana

As part of their community outreach program, HASA visits patients at home twice a week. Patients receiving compression therapy visit the clinic on Mondays and Thursdays for treatment.

Mukansenga, the trained community health worker (CHW) adds, “We educate communities on the importance of using mosquito nets for Lymphatic Filariasis (LF) and wearing shoes while maintaining foot hygiene for Podoconiosis (Podo).”

“We’ve witnessed success stories where girls who once relied on walking crunches have regained mobility with proper shoes. Some have married, started families, and been welcomed back by their husbands after treatment. Others are working and moving forward with their lives,” notes Uwizeyimana.

At 15, Emmanuel Nyirishema developed elephantiasis, experiencing high fever, gangrene, and severe leg swelling that left him unable to walk. When he sought help at a local health center at 18, he was told they couldn’t provide treatment.

Thanks to the collaborative efforts of the Government of Rwanda and WHO, Nyirishema’s condition improved. In early 2021, he finally received the necessary treatment at Kinyinya Health Centre. “I had suffered from terrible wounds,” he recalled. With the treatment, Emmanuel is now able to walk again, living without pain or disability.

“Before I started receiving treatment from HASA, I felt so isolated and hopeless. But the foot care, compression therapy, and support groups have made a huge difference. I’m able to manage the swelling and pain much better now, and I even feel confident enough to go back to working on my farm,” notes Nyirishema.

Despite these efforts, challenges remain in rural areas, where access to care is limited. The stigma surrounding the disease, coupled with financial barriers, prevents many from seeking the treatment.

Nyirarukundo’s experience highlights these challenges. “Even with health insurance, I couldn’t afford the treatment,” she says, highlighting, “ I was referred to Kanombe Hospital in Kigali, but financial constraints have made it impossible for me to travel for treatment.”

While Nyirarukundo, Mudaherana, and Rukundo may feel their disease are incurable, Uwuzeyimana notes that LF and Podo can be managed with proper medical treatment and wearing shoes but emphasizes that the biggest challenge for patients in rural communities is the long distance to clinics, while some patients head to traditional healers, who are not equipped to offer treatment.

“The information gap is evident, as some patients return for treatment after three years. At times, we [HASA] wonder if they have passed away, but they return based on how they feel. Unfortunately, some never come back for treatment,” Uwuzeyimana points out.

For Nyirarukundo, who hasn’t received medication since 2004, the biggest challenge is the distance from Kayonza District to Kigali City. While Mudaherana, after 22 years of suffering, has also accepted the uncertainty of healing. “I’ve come to terms with the reality that healing is uncertain,” he adds.

While the prevalence is not as high as in countries like Ethiopia, Uwizeyimana emphasizes the need for collective action to address LF and Podo. “It’s a double burden, as many people are unaware of the causes and lack both information and financial resources,” she explains.

“Together, we can make a real difference,” she says. “Each effort—be it treatment, awareness, training, or compassion—improves the lives of those affected. A multisectoral approach is essential, encompassing outreach campaigns and advocacy.”