As with each Global Health Compassion Rounds, we have an opportunity today to delve into a specific area of focus and explore the important linkages with compassion. Today, the subject is the movement to eliminate neglected tropical diseases (NTDs). Our intention, as always, is to share our thinking, to challenge each other, and to hopefully spark new thinking on a subject matter that is incredibly important for populations across the world.

I’d like to say a few words about NTDs for the audience who may not be familiar with that term or understand the impressive programming that has developed over the last few years. After many years of trying to get traction, funding, and interest in these “diseases of neglected people,” in the early 2000s, the WHO led a group of enterprising people who wondered what would happen if these diseases were bundled together. If combined, how would they compare to the big three—HIV, malaria, and tuberculosis?
As it turns out, when measured by disability adjusted life years (DALYs), the burden of the 17 diseases that were considered at the time was clearly greater than that for malaria and tuberculosis, suggesting that coming together would actually help in promoting the control and elimination of these diseases.

NTDs are really diseases of neglected people. They tend to overlap in the same area. In many areas, all five or six of the common NTDs are present in the same country. NTDs are markers of poverty. They affect health education, development, gender equity, and there's a vicious cycle between poor health and poor development that has been really persistent in many of these areas. The initial strategies to address NTDs unabashedly proclaimed themselves as “pro-poor.” This was not just about alleviating disease, but it was about promoting development and well-being, particularly for those who are least economically resourced and who are affected by these diseases.

The current list of 20 NTDs occur largely, but not exclusively, in tropical areas. Most of them had received limited attention before being bundled together under the NTD rubric. There are several strategies for addressing these diseases since they're so diverse. I’d like to highlight a few of the major ones. Preventive chemotherapy, or mass drug administration, is the periodic delivery of single doses of medication—usually once every six or 12 months to reduce transmission and to alleviate disease. There are currently five diseases that are primarily addressed through preventive chemotherapy.

Another major strategy involves intensified disease management—bringing the correct tools and diagnostic modalities to take care of these diseases within the context of primary health care. Certainly, vector control is very important for NTDs. Water, sanitation, and hygiene is crucial, as is control of zoonotic diseases, which many of these diseases are. So it's a rather multifaceted bundle of interventions that are used to address these 20 diseases.

I’d like to turn now to compassion. As Shams mentioned, we look at compassion as a three-part equation: awareness of suffering, the emotional attunement to that awareness (empathy), and then action to relieve and prevent suffering. I would argue that the NTD movement has been very much aligned with these three elements.

In addition to the physical suffering of the disease manifestations, from very early on, investigators and scientists were aware of the other realms of suffering these diseases provoke, such as stigma. This has been part of the awareness of suffering in the NTD movement for years and front of mind for those who have been charged with trying to control or eliminate these diseases.

There was an element of empathy in the early materials for the lymphatic filariasis movement. Many people who worked in areas where these diseases occur were very moved emotionally by the levels of suffering that these diseases cause.

And then action. Tremendous action, both on the clinical side—for example, in the case of mass drug administration, which now reaches 1 billion people worldwide—as well as in the efforts to organize, implement, monitor, and evaluate all these activities. So I would argue that the NTD movement has been aligned and organized around the elements compassion from the beginning.
The NTD Roadmap: A Blueprint for Compassion

Jonathan King, Team Lead, Community and Primary Care Based Interventions, Dept. of Control of NTDs, World Health Organization

I know that many of you were expecting our director, Dr. Mwele Malecela, to speak today. Unfortunately, she's not well and unable to join us. Compassion is very close to her heart, and she's living example of compassion in her work and in her leadership. I fortunately get the opportunity to have this discussion with you all.

One thing I can say after having nearly all of my working career in NTDs is that the community is filled with passionate and compassionate people from all walks of life, from all levels, from all stakeholders. It's been a tidal wave of compassion of love and kindness poured out among the NTD community, not only to initiate these programs, but also to sustain them to see the tremendous progress that's happened to date. I think we're all on the same compassionate vision: a world free of suffering due to NTDs and communities not hindered by preventable diseases. These are preventable, avoidable diseases. Not one person should have to suffer due to lymphatic filariasis or trachoma or any other NTD.

There are a couple of questions that I think we should ask ourselves in life. One is, “What is the purpose of life,” and the second is, “What are we going to do with our life?” I don’t know if I have all the answers to number one. But I was moved by compassion in response to the second question. This became clear to me in my very first encounter with someone with lymphatic filariasis (LF), a man affected by hydrocele. I was in graduate school and had just written a paper on LF, and then a few months later, I had this interaction and felt empathy toward the gentleman’s situation. In that setting, I could not provide help for that person. But I knew this was LF, I knew this is an avoidable condition, and I can do something about this. I believe that experience shaped my working career. Every time I have interactions with persons affected by NTDs, it’s a blessing for me. It strengthens my own personal commitment and reason for working in NTDs. And I think this is common among the community.

You're all aware of the NTD Roadmap, which several of you contributed to. This document sets the global targets for control and elimination of NTDs through 2030. Not only does it have the targets, it really is, I think, a blueprint for compassion. Carrying out the goals in this document is a way to express our compassion. At WHO, we’re definitely grateful for the community and all the commitment put towards making the goals of the roadmap come to fruition.

There are certain themes in the roadmap that bring out compassion. Obviously, disability management, disability inclusion, and the focus on person-centered care. The desire to have the awareness and the desire to do something about the suffering was, I believe, the main motivating factor for countries and stakeholders and the commitment to the World Health Assembly resolution for eliminating lymphatic filariasis. It’s also this commitment that has kept morbidity management and disability prevention as one of the core aims of the global program to eliminate LF.

There are other cross-cutting things, as well, like the incorporation of safety. David mentioned that we provide about one billion people with preventive chemotherapy to interrupt the transmission of NTDs, and we place special attention on ensuring that no harm is done through this process.

Capacity building is another cross-cutting issue. A core theme of the roadmap is to shift to country ownership. I think when the NTD community was initiated, there was a sense of partner-led activities and priorities. I believe that we need to shift to country-led decisions and for external partners to listen and to be attuned to the needs of countries that are working and investing their time to avoid suffering and eliminate these NTDs.

In closing, I would just like to express the commitment of WHO. I think this roadmap provides a way for us to express the compassion in NTDs and to bring in new commitments and financial commitments from stakeholders. Now is the time to demonstrate commitment to this cause, and through that, reflect the compassion we feel and what drives us to eliminate these diseases.
Examples of Compassion in Onchocerciasis Response
Uche Amazigo, Retired Director, African Programme for Onchocerciasis

The foundation of the global response to one of the world’s most devastating NTDs, as far as I know, has strong elements of compassion. I will talk about compassion in the delivery of healthcare using onchocerciasis and drug distributors as examples.

First, let me explain river blindness, or onchocerciasis. If you have time, please read Bruce Benton’s recent book, Riverblindness in Africa: Taming the Lion’s Stare. It has everything you need to know about compassion in health care delivery and river blindness in sub-Saharan Africa. River blindness is the leading cause of visual impairment and skin disease, which can lead to disfigurement, unrelenting itching, and social stigma both in men and women, but it really affects the young women more.

The World Bank’s creation of the Onchocerciasis Control Program in West Africa was based on compassion. The compassion of the World Bank staff led them to demonstrate a link between health and development in their initial report. That was followed in 1972 by the trip of the World Bank President, Robert McNamara, and his wife to Upper Volta (now Burkina Faso). During that trip they visited villages along the Black Volta River. They saw so many blind people, many of them being led by young boys who could no longer go to school.

They did not go there for onchocerciasis—they went there to look at the impact of severe drought on the region. And when they got there, they were taken by one of the French scientists to one of the villages along the Black Volta River, and that’s where they saw so many blind people. On the spot, President McNamara decided he was going to create a group to fight river blindness. That led to the launching of the river blindness control program, the Onchocerciasis Control Programme (OCP), which covered 11 countries in West Africa. Their activities at that time were to suppress the black flies to liberate people from the bite of the black flies, which causes river blindness.

If you read the reports of the OCP, there are so many stories demonstrating elements of compassion. The compassion of community leaders, of community people, the compassion of the pilots who carried out the aerial larviciding, the compassion of the scientists who spent nights in the field collecting flies, dissecting them, and trying to determine the best larvicide to apply each season. We also had the unprecedented donation of Mectizan® by Merck & Co. in 1987. President/CEO, Roy Vagelos, announced that it will be free for as long as it is needed for those who need it. That was a clear demonstration of compassion for the poor.

After the donation, the next thing that happened was the onchocerciasis disease study in 1990, which led to the story of Agnes and myself. I was fortunate during one of my weekly visits to communities to talk to women on nutrition and health, I met this 19-year-old pregnant girl, Agnes. Out of compassion, I started paying for her treatment. I reported the whole experience back to WHO/Geneva, and that led to the 1990 pioneering study on onchocerciasis skin disease. Again, this is compassion.

The success of OCP activities, the study on Agnes, and a subsequent WHO multi-country study led to the creation of the African Programme for Onchocerciasis Control (APOC). Agnes became the face of APOC. Compassion was the prominent force throughout the existence of APOC. There are five contributing forces, and all had elements of compassion. One, I had already mentioned the breadth and length of Merck’s donation. Then the story of Agnes with debilitating skin lesions. Now the NGOs that joined APOC were already working on river blindness prevention programs. They were coming in contact quite often with blindness cases and saw its devastating effects. And you can imagine that many of those NGOs, some of whom are still working today, had compassion for the blind and wanted to find a solution.
Then the leadership of the WHO’s Special Programme for Research & Training in Tropical Diseases (TDR), Dr. Tore Godal. He is a very well-known outstanding scientist and leader on leprosy control. His decision to fund research on onchocerciasis skin disease demonstrates his compassion towards NTDs and that he wanted to eliminate leprosy.

I’d like to zero in now on the NTD drug distributors. Community drug distributors (CDDs) face numerous challenges to bring drugs to community members year in and year out. Let’s take the example of Kaduna State, Nigeria. In the PLoS NTD publication released this year, we found that in the 23 local government areas of Kaduna State, over 1,500 CDDs have served for more than 10 years distributing NTD drugs. Half of them have served for 18 years, many without any remuneration.

Ghana has even more impressive results. Over 9,000 CDDs, including females, have served their communities for more than 10 years, and one-third of them have served for 18 years. I don’t see any better way to describe their compassion for your community members if not by making sure they swallow these drugs every year in order to free them from neglected tropical diseases. Overall you’ll find that CDDs receive about one-tenth of the total value of opportunity cost they incur. But do they mind? No—they have compassion. They want relief for their community members.

Lastly, I’d like to talk about the distance that CDDs take. In one extreme case in Liberia, one could only reach the village after five to eight hours of trekking. We tried to estimate the average number of days that CDDs from Tanzania, Cameroon, Nigeria, and Liberia walk in a year to distribute NTD medicines to community members. We found the minimum is 14 days, the maximum is about 21 days.

You see, the whole NTD world—the NGO partners, the donors providing the funds, the ministries of health staff, WHO, the community members—they have formed a strong partnership and compassion is a thread that runs through their actions. Awareness of the suffering of the poor and empathy underline their day-to-day and year-to-year actions.

I don’t see any other way of describing compassion for your community if not by making sure they swallow these drugs every year to free them from NTDs.

Examples of Compassion in Lymphatic Filariasis Response
Suma Krishnasastry, Professor of Medicine & Director of Filariasis Research Unit, Government Medical College, Alappuzha, India

I’m going to speak about another NTD—lymphatic filariasis—and how compassion is being practiced in lymphatic filariasis (LF) elimination. LF is now endemic in 72 countries. The chronic manifestations of LF are chronic lymphedema, hydrocele, and acute adenolymphangitis or acute attacks.

The global program to eliminate LF has two arms. The first is to stop transmission through mass drug administration. The second is to alleviate suffering and improve the quality of life for persons affected, otherwise known as morbidity management and disability prevention (MMDP). MMDP has several components, like managing the lymphedema, treating acute attacks, management of hydrocele, and treatment of remaining infection.
In NTDs and in LF, the most neglected part is the patients. So the question is, how can we improve patient care? We have learned from the previous speakers about the components of compassion. First you have to be aware of the suffering of the person. And when you are aware of the suffering of the person, there should be an emotional resonance—that is empathy. It doesn’t stop with empathy—there should be a desire for action to alleviate the suffering. So there should be empathy plus action, then it becomes compassion.

Apart from their physical problems or the disease process, patients with LF experience a lot of suffering. With regard to the physical suffering, when they have lymphedema, they are not able to move around easily. They are not able to use the public transport system. And they may not get an adequate job because of the physical disability. There are also a lot of psychological problems, because this disease has a lot of stigma. Previously, if there was a family member with lymphedema or hydrocele, they were not allowed to come to the front of the house when there are guests, or they were not allowed to attend functions. The social exclusion of this stigma causes psychological effects for the patients. Patients also suffer economic problems. They get recurrent episodes of fever, and when that happens they cannot go to their job—they have to be in bed for about 10 days.

You can’t just clinically manage the lymphedema in these patients and leave them alone. There is a lot of suffering, and it is the health care provider’s primary responsibility to know this suffering, and that involves compassion. For proper management and treating the patient as a whole person, what is required? Clinical excellence, as well as compassion. These should go hand in hand.

You cannot just treat the patient and not have emotional resonance. And compassion alone also will not be enough for the management of patients. So we should always have clinical excellence along with compassion. There was a question whether there is a conflict between technical care and compassionate care. I don’t think so because they should go hand in hand. As I said earlier, there should be proper technical care, and along with that there must be compassionate care also.

There have been large studies where the effects of compassion have been measured, and there are definite clinical effects when you have empathy towards a person affected and when there is action following that. The first one is a physiological effect. It is said that when you talk to the patient, you should be a good listener. Pain perception decreases for the patient as a result of an empathic approach to the patient. Additionally, persons suffering from stigma will be more confident when you approach them with compassion. They feel you are somebody with whom they can share all their problems, and studies show this decreases the patient’s depression, anxiety, and other psychological problems.

The third effect is improvement in patient self-care. You may give the patients drugs, but once they are out of the hospital, they have to take the medicines on their own. If you approach the patient in a compassionate manner, the patient gets confidence from the health care provider and feels he must take these medicines regularly. LF patients are also susceptible to acute fever, which is due to bacterial infection. To avoid this, patients are required to undertake certain hygiene practices. They also need to do exercises, elevate their limb, and use proper footwear. All these things are not just for one day, it should be for the rest of their life.

So when the patient comes to our hospital, we train them. We first tell them what to do. Then somebody in the health care provider team shows them how to do it. And finally, we make them do it, so they are able to continue it at home. After some time, they’ll understand this is for them, and they definitely get improvement with this. We have recorded and found a drastic difference, which helps them in daily life, which improves not only the patients’ quality of life, but it is also perceived as quality care. So the compassionate approach can make a lot of difference for the patient—physiological, psychological, patient self-care, and quality care.
I’d like to share some comments from a patient:

The doctor told me to wash my legs daily with soap and water before going to bed, to apply the ointment regularly, to keep the legs raised while lying down, and to avoid injury. I do not have any difficulty to carry out these instructions. I am saved now only because I carry out these instructions regularly. Otherwise, my leg would have been worse than this.

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I helped a person by washing his legs when I found that he had huge swellings on both legs with ulcers. There were maggots in the ulcers. I watched his legs myself using soap and water and applied the ointment given from here in all the folds of the swelling. The relief of his pain and itching after I did this was remarkable. The next day again he came asking for some ointment.

Here what happens is that the person is ready to help another affected person. The compassion from the healthcare provider has already been transferred to the patient, and the patient is trying to give it to everyone around his or her area. Later what happened was they formed self-help groups in which they were educating other people. In that process, there was also considerable reduction of stigma.

I have helped others who have this disease. One teacher in our place had a very large swelling which was always oozing and was foul smelling. I told him that if he kept his legs clean by washing daily with soap and water there would not be any problem. I have also instructed several others in our locality regarding this treatment.

When the healthcare provider treats or approaches a patient with a lot of compassion, that will be reflected back to the health care provider, as well as to their fellow human beings. Because to be aware of the patient’s suffering we first of all have to be better human beings with some humility also.

From the point of view of health care providers, it produces inspiration and motivation. I joined in Alleppey Medical College from a different district, and I thought of going back after three years. But I got involved with this lymphatic filariasis program, and now it has been 32 years. During that time, we were doing training for the doctors and nurses at the Kerala hospitals as part of the Sustainable Development Goals program. Initially, they were not very happy that they had to attend the training, because they said, “What is there to teach us on LF for four days?” But later on, they realized they were not aware of many things, and they found they could help the patient by simple methods they did not know before. We had patients there during these trainings, so the health care providers were interacting and listening to the patient and their suffering. This also increased their compassion and motivation, and also reinforced and strengthened their clinical practice.

I would like to say about word about this patient. She had lymphedema from the age of 15, and she had suffered a lot. She used to be a tailor, but she couldn’t do that because of the swelling and recurring episodes of acute attack and fever. Because of that, she tried to commit suicide. Then she was put in our program, and many sessions later, she gained a lot of confidence and started looking after herself.

Now she’s living with her sister and niece, who takes care of her, and they have a very big bond. Her dream is to be educated and get a job. And she behaves normally, even though her limb is big. Change is possible. And when you see your patient’s eyes sparkling and a smile on their face, that is the best thing that can happen to me as a clinician. I think everybody should be approaching persons affected with NTDs with compassion.

I will end with this quote: If you see someone falling behind, walk beside them. If you see someone being ignored, find a way to include them. Always remind people of their worth. One small act could mean the world to them.
Listen Humbly: Perspectives from Affected Persons
Mathias Duck, Global Advocacy Manager, Leprosy Mission International

During my first year as a chaplain, I was diagnosed and treated for leprosy, and that added a whole different perspective to my work and to the way I encountered people. It was during this time I realized we had tried to encourage people to talk about their experience of leprosy, and we said we should treat it as any other disease. But once it happened to me, I realized that wasn’t quite as easy as I thought it was.

I had heard from so many people, and I thought I knew what they were going through. Going through it myself was quite different, however, because I was not going through it in the context of poverty, lack of nutrition, or experiencing stigma and discrimination. I could only imagine how much more difficult it had to be for different people who were experiencing so many other adversities. That’s how I got involved, I think—moved by compassion, moved by hearing what people go through and hoping to make a difference with my story.

Additionally, in my role right now, it is very important for me to listen to people, because every experience is different. People experience this disease differently. COVID has shown us that the situation for most persons affected by leprosy—I don’t know how it is for the other NTDs, I suspect it’s similar—has exacerbated all their needs and problems. So one of the things I try to do, and I try to advise others, is to listen humbly.

When we talk about awareness and empathy, those are probably never boxes that we can check, that we can say, “I've got enough awareness, I don't need to be more aware than I am right now,” or “I have enough empathy,” or “I have enough humility.” In fact, if we do that, we might prove the opposite. This is something that I’ve been learning for myself, and I've tried to encourage other people to do—that we continue to listen and seek awareness. And we continue to grow our empathy and our humility.

I used to be identified with the hospital, then with organizations of persons affected. Now I am still identified with organizations of persons affected, but also identified with an NGO. Coming from an NGO perspective, when persons affected ask critical questions, sometimes we might have a tendency to feel attacked, or even say, “Why are they not grateful for all the things being done for them?” And I am trying to learn, even when the questions are tough and when there is criticism, to listen very humbly and learn. Because persons affected—and in the case of The Leprosy Mission, persons affected by leprosy—are our reason for being as an organization. And we have decided as an organization that we want to center them. So we need to listen to them, and we can learn. Because if what we think is the best we can do is not the best for them, and if it’s not improving their lives in all aspects, then we need to improve.

So the main point that I would like to communicate today is: listen humbly, especially when there are tough questions and criticism.
Practicing Compassion at an Organizational Level

Girija Sankar, Vice Chair, NTD NGO Network; Head of NTDs, Catholic Blind Mission International

I've organized my thoughts and reflections under three themes. First, I'd like to reflect briefly on how I approach the work I do, and how I interpret compassion in my global health practice. Then I ask if compassion is measurable. How might organizations practice compassion in timeline- and log frame-bound projects? Finally, I end with a reflection on the tyranny of words, or well-intentioned words.

In 2015, I met some children on a trip to Mozambique. I was there to observe and learn from an annual mass drug administration campaign for trachoma. I was walking around getting a sense for the village when I ran into them, and as visitors usually tend to do, I showed them my photos from my smartphone and we all had a good laugh over it. When I reflect on these moments from visiting endemic communities, I wonder if the word compassion, and by extension, this notion of suffering, is perhaps limited in capturing the full lived experiences of people who are at risk of NTDs but also have other life experiences the way that you and I do. And I wonder if the idea of compassion, meaning to feel another being's pain and suffering, is perhaps more representative of a biomedical perspective.

While I understand and appreciate the intense pain, suffering, and stigma caused by NTDs, as a non-medical public health worker, it is empathy of shared feelings, not just of pain and suffering, but also of joy or the merriment that I perceived in those children, that guides my everyday work.

Earlier on I asked if compassion is measurable. For NGOs, it matters that the work we do is measurable, scalable, and replicable. We’re also driven by demands for fiscal prudence, timely delivery of program interventions, and robust epidemiological evidence of the NTD interventions. It might seem as though the exigencies of largely donor-driven public health interventions for NTDs would render any attempt to practice compassion a difficult exercise. The idea of practicing compassion at an individual level makes sense to most of us. In fact, fellow panelists have all talked about the compassion of health workers, the compassion of scientists collecting flies, the compassion of community drug distributors. How does the idea of practicing compassion at an organizational level make sense, or does it make any sense at all?

Rather than answering that challenging question, I ask if we might examine some of the work we have already done and ask if the practice of compassion is evident in our intent, our language, and our suggested approaches. Where does compassion manifest in our resources? To that end, I reviewed some of the scholarship produced by the NTDs NGO Network and its members. Each of these pieces of work represent the collective experiences of NGOs. Each represents a desire to promote care for the person, instead of focusing solely on the disease. This is particularly the case, I would argue, with the guide on stigma and mental well-being, which acknowledges that often people affected by NTDs may not be treated in time, or not treated at all, and suffer from disabilities and impairments. In acknowledging that NTDs can not only cause pain and suffering but also stigma, this body of work starts from a place of compassion.

Finally, a reflection on the tyranny of words. How we express what we do signals how we approach our work. Words matter. Is the practice of compassion evident in our language? Our everyday jargon? Is every member of every community affected by NTDs a “patient”? Or perhaps an active participant in a public health program? As a non-medical public health practitioner, again I’m uncomfortable using the word “patient,” while it might be entirely applicable to Dr. Suma, who is in fact a frontline service provider.

How about the word “beneficiary”? Is that signaling compassion, or is it signaling pity and charity? A few other words that we employ, like “capacity building.” I use that all the time, but whose capacities are we building and for how long? Or “intervention.” I’ve used this word already a couple of times in this short presentation. How can a practice grounded in compassion be an intervention? Maybe it can, but these are some words that jumped at me. And finally, “human interest story.” Isn't every story a human interest story?

Thank you so much for your attention.
DISCUSSION

Moderated by Shams Syed

Shams Syed: What a wonderful set of perspectives and thoughts. I’ve certainly learned a huge amount just by listening to the wisdom of these colleagues, and we’ve had expertise from different parts of the world, different continents, and different deep dives into specific neglected tropical diseases. I would like to start with an excellent question that’s emerged from those who have joined us today: Is compassion contagious?

Uche Amazigo: Yes, in some circumstances, you can say that compassion is contagious. What comes to my mind is the initial hesitancy of community drug distributors (CDDs). Some are selected by their communities to serve them, and so they hesitate. But then they begin to see their colleagues doing that, going from house to house distributing NTD drugs, and you’ll find a number of them coming back to their community leaders, volunteering to serve their communities. So that’s one example of compassion being contagious.

It’s also contagious if you look at the demand for incentives. We have experiences from all NTD programs that CDDs demand cash incentives. And they are right to do that, but we cannot pay them cash incentives, otherwise the programs will collapse. So the NTD programs now depend on those who are volunteers. There are reports that people who were hesitant at the initial stage because they had no monetary incentives would come back later and join the crusade of volunteer CDDs.

There are also instances at a higher level where I would say compassion is contagious. From my experience in APOC, working with over 20 countries and 14 international development organizations for almost 20 years, I realized that at the initial stage when the donors come to a meeting, not all the officers really appreciate listening to communities and building trust with communities—you know, showing that emotional response to people who have pain. But over time, you find that they begin to buy into it and even become crusaders. When they review reports, they begin to ask, “Well, what did the community say?” What Mathias said earlier becomes extremely crucial to them. They want to hear from the one who feels the pain, they want to be part of the pain of the people.

Suma Krishnasasty: Yes, definitely, compassion is contagious. I feel that it should be and it must be. Even if there is a person who thinks the healthcare provider should not be listening to the patient, or that you should not be spending a lot of time with them. If that person goes on listening, and, after some time I am sure that the person will start doing that, because that’s a beautiful feeling. It benefits the patient or the persons affected a lot. As healthcare providers we must be doing that. Compassionate care should be part of everything we do for the patient.

Mathias Duck: Well, I don’t know if there’s any evidence on this—perhaps David can enlighten us on that one—but I think in the end, compassion is like an attitude. Sometimes you say that negativity is contagious, or positivity is contagious, and we can certainly say that with leprosy. Even when we look at other situations in life, sometimes hate and prejudice can be contagious, so I think compassion is and can be contagious. Perhaps we have rival attitudes we have to deal with. But I think the way you encounter a patient who is stigmatized by the community, you can make a difference. Perhaps it will not be automatic, but you can make a difference. The community sees how you encounter that patient, and the community starts to see that person in a different way.
We want them to move from the despair of feeling neglected to being appreciated as human beings in their communities.

Girija Sankar: I actually have two responses. In the short term, yes, compassion is contagious. In the long term, I don’t know, because right now, let’s take the example of the earthquake in Haiti that just happened a few months ago. We all wanted to do something. We want to write a check, we want to be doing something, and perhaps we also want to be seen as doing something. In the long term, is that sustainable? Is that ability to empathize with another person’s suffering over the long run sustainable? I don’t know.

On the contrary, I look to this NTD community and think about how small this community was just a decade ago. I think about how much it’s grown and about the phenomenal advances we have made. So clearly, looking at the evidence that’s presented in front of me, I have to say yes, indeed, compassion is contagious.

Jonathan King: I felt I had to do some self-reflection, because I use the word “capacity building,” and Girija just told me that wasn’t appropriate. So what do we mean by that? And I’m going to tie this back to the “Is it contagious?” question. What we mean by “capacity building” is teaching a skill out of compassion. We want more people to learn so they can then apply that learning in a way of compassion to help others.

I’m surprised Suma didn’t bring it up in her answer, but she spends a lot of time starting these self-help groups. She has to teach new skills to people who are affected with lymphedema, and she shared quotes of those who are affected by lymphedema and LF. Teaching another person, seeing someone in the community who could use those skills and use that help—that is an act of compassion. In some of the capacity building that Suma does, she gives so much in running workshops, teaching program managers in LF endemic countries, or program managers who may have come from other areas of primary healthcare or public health and are new to LF. I’ve witnessed some people coming into those workshops who seem maybe not the easiest of personalities. If you saw them, you would think, “Where is the compassion in this person?” But by the end of it, through Suma incorporating compassion in the training, it’s really rewarding to see the change and the contagion of compassion.

Shams Syed: I’m going to dig just a little bit deeper now with each of the panelists. There’s an excellent question coming through related to the word “neglected” in neglected tropical diseases, and whether that actually elicits pity rather than compassion. This is also linked very much to the tyranny of words that Girija highlighted earlier. Keeping that in mind, I want to probe a couple points each of you made.

Uche, you told a remarkable story of Agnes. How did Agnes feel about her role in catalyzing global change? Suma, I was going to come back to you about your emphasis on patient care and clinical management. Do you feel that the word “neglected” has a meaning beyond what it should, in terms of this point that the colleague has asked? And then, turning to Mathias, particularly on this wording issue, as somebody who has been affected by leprosy.

Uche Amazigo: Thank you very much. I want us all to remove our hearts and put on the heart of Agnes—a 19-year-old girl, pregnant, who was sent away by her husband, filled with itching lesions and unable to sleep. I wonder how you would feel in that situation—neglected? I would think so. But Agnes rose from that. After receiving ivermectin for a number of years from The Carter Center program, the neglect that she felt was removed. Her lesions disappeared gradually, and with time, Agnes became a community drug distributor. For more than 10 years now, Agnes has been a CDD of the same ivermectin that saved her. Moving from that initial pain of feeling neglected, she also rejoined her husband and now has four children. So the word neglect is good, but we want people to move from the despair of feeling neglected to being human beings who are appreciated in their communities.
Suma Krishnasasty: Regarding the clinical management, there was a stage where persons affected were neglected so much. I work in a hospital that is in an endemic area where the prevalence used to be very high; now things are changing. Previously, a person with lymphedema was never treated with the same dignity as other people, because the leg may be foul-smelling, or may be oozing, or the appearance itself makes people move away. When I joined here, there used to be a ward where all the legs are being kept—a “ward for the legs.” Not only that, they may be given some analgesics or antibiotics but no more than that. So many of them never wanted to go to the hospital, because they knew they would be kept in a corner of the ward somewhere and they would not be taken care of. But things have changed a lot now. Knowledge is now widespread and many people know that simple methods of hygiene can give a lot of relief for the patient, and we can help them a lot.

Now the name "neglected tropical disease" is gaining attention. People have started asking, "What do you mean by NTD? Which diseases come under this?" This attention is helping advocacy, also. So it is not the correct time to change the name.

Mathias Duck: I think David made some effort when he introduced us to mention, at least two times, that he did not talk about NTDs so much as that he talked about “diseases of neglected people.” And I wrote it down here: NPDs, neglected persons diseases. We’ve had this discussion already in the NGO NTD Network, and I think there is something to it. How did these diseases change before we even learned what the bacteria is? There used to be leprosy colonies all over Europe. It changed because people got better living conditions. If we really want better, if we really want to fight these diseases, then we have to look more structurally at some of the things that are going on in certain parts of the world more than in others.

If we talk about compassion and pity, language matters. For some of us, English is not our first or our main language. I know that in Spanish, those terms sometimes get mixed up.

I also think that we should examine ourselves. Sometimes we come from a position of, I don’t know if it’s superiority, but there is a power imbalance, or there is a knowledge imbalance, or there is prestige imbalance. Or we come with an organization, and we have the power to decide things. And I think we should always examine ourselves: am I seeing this person as an equal? So I think that will determine if it’s pity or if it’s compassion that is within us.

Girija Sankar: I’m with Dr. Suma here—I think the term "neglected" serves a very important purpose. I think it elevated awareness around the need to address diseases that were affecting millions of people that weren’t necessarily getting the attention they deserve. So, absolutely, it served a purpose. But I think today is also the right time to ask these questions. Like one commenter had said, when you say “tropical diseases,” it conjures certain images and notions, and it harkens back to Mathais’s point about power asymmetries. It’s “tropical = neglect/bad,” and “temperate = good.” So I think it’s a good question to ask.

Jonathan King: Coming from the Department of Neglected Tropical Diseases, I was thinking, about the word “tropical,” too. The Pan American Health Organization (PAHO) decided to use “Neglected Infectious Diseases." And I think “neglected” really did serve a purpose to increase the advocacy. We all should be grateful for that, because it brought more resources into the work that needs to be done. At the same time, “neglected persons diseases” really cuts to the point of the person-centered approach. It’s the person affected that we have to bring attention to and that we have to listen to, as Mathias said. Are our aims and intentions really meeting the needs? Or is that what a person needs? We need to reflect on that. With NTDs, it’s okay to continue using this, but I think it is nice to have this discussion around what is the focus and what does it portray.
**Shams Syed:** One of the things I wanted to end on is the point, Jonathan, you're making about people-centeredness. A fundamental point that WHO has been emphasizing in terms of people-centered health services, people-centered health systems, and of course the linkages with creating quality health services is evident and clear. We won't have the chance to go into depth in that, but that's also something that we could perhaps spark as a discussion from this point. People-centered health services is a core component of quality health services.

It's been a remarkable 90 minutes. Handing it over to you, David, to close us out.

**David Addiss:** Thank you very much, and that's a nice segue to say that the new NTD roadmap that Dr. Malecela pioneered and developed in great collaboration with all the partners really does take person-centered care as a central pillar. So the whole NTD movement is on a trajectory of person-centered care already, thanks to Dr. Malecela's leadership.

I would like to thank all of the presenters and the audience who have stayed with us for a few minutes overtime for such a fascinating, rich conversation. I want to say how grateful I am for this opportunity to lift up the theme of compassion in NTDs. Compassion really does seem like the engine, the fuel that drives all of this activity, this amazing body of work, this community of practice that is making such a difference in the world. Our Rounds today speaks to the power of compassion. We heard several testimonies to the power of compassion in individual lives, in programs. I want to note that we don't often think of compassion and power in the same sentence, but I think we've borne witness to the power of compassion to alleviate suffering and to move us as human beings.

Part of our reason for being together is to challenge each other. Mathias reminded us that we don't just achieve compassion once, and then we've got it. This is a continual process of exploration, of having the humility to question our own words, our assumptions, and to exchange ideas with each other so that, as a community, we can become even more compassionate and more effective. I really want to thank the colleagues who have raised questions for us to consider today—we will carry those questions forward. Those questions help us perfect and mature our compassion, both as individuals, and as organizations, and hopefully as a field.

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