

Equity and Access to Health & Social Services Experiences From Congo Dr Chiara Castellani

For me talking about equity means talking of something that is real and not an abstract principle, that was part of my two contrasting experiences. For seven years, I worked in **Nicaragua** with Sandinist Government. About the policies of that government, there may be many criticisms, yet undoubtedly, it was a period in the country when access to essential drugs was guaranteed. Access to preventive and curative services, especially for the poorer sections of the society was guaranteed. The health services did have clear criteria like to give priority to groups like children, pregnant women, tuberculosis patients, etc.

Then in 1991, I came to **Congo**, which was called Zaire at that time. I was very new there and I saw a sixteen-year-old boy, to whom I diagnosed appendicitis and proposed that operation was necessary. However, I was shocked because the boy was not operated till the family could put together the funds for the operation. By that time, the boy already had peritonitis and any way, the family did not have money to pay for antibiotics. Thus that sixteen-year-old boy died in front of me, a stupid death, which shocked me since I was coming from a completely different context.

These last 10 years in Congo have been a continuous battle to ensure services to those, who do not have the money to pay for the services. As far as access to essential services and drugs is considered, in our area of Kimbau, the situation is quite desperate and it is not easy to find solutions. To look at the question of equity, let me start with a story called, "Death of Mrs. Victorine".

Why Mrs. Victorine is dead?

- Too many child-births, one after another
- The pressure from the family for another child
- Malaria and anaemia
- Poverty and isolation
- No Anti-natal check-up
- No prophylaxis or treatment

Among the many tragedies, which are part of life in Kimbau, there is also the story of Mrs. Victorine. Victorine was also a good friend for me. She was together with my close friend and guide, Dr Isha, our old doctor who worked as chief medical officer and who was shot dead by military because he was originally from Rwanda. Victorine stayed with him till, his very end, refusing to leave him. Then she fell in love with Albert, who is from another village. They were

married and so Victorine left us to live in Albert's village. I was informed, when she lost her first baby. It was a spontaneous abortion and she had bad haemorrhage. She should have waited for some time before becoming pregnant once again, but there was family pressure. She had "failed" once and she had to prove it to the family that she was a fit wife for their son. However, she was not fit to have another baby so soon. You know, in malaria endemic countries like ours, if there are repeated pregnancies, the risk of anaemia become much higher. In the place, where Victorine was living there was no possibility of treating her anaemia, there was no prophylaxis against malaria, and there were no iron tablets for her. They did have a peripheral health centre in her village, but in a country where health services are not organised, for economic reasons, nurses become transformed in to merchants and every thing is only for sale, only if you can pay the price. They did not even have Chloroquine in their health centre. There was no iron, no Chloroquine, both drugs needed by Victorine during her new pregnancy. During that pregnancy, she did not go for any antenatal check-up. I came to know about all this, much later.

WHO has made a video, "Why Mrs. X is dead?", where instead of Victorine, they have an "X". To that video and that story, I have given a name. I had seen that video and it had been impressed in my mind as the story of a woman, where the medical intervention is too late and after a futile caesarean section, both mother and the baby die. WHO says that it is a true story. Victorine's story is even more real. She did not even get any caesarean section, as she did not have enough money to pay for any operation. She died along with her baby, without any one doing any thing to save her or her baby. Why did she die?

They called on the radio, "Come quickly. Victorine is sick". Actually, they did not call me or ask for me. The message was for Victorine's father. I only went along because she was my friend. When we arrived in Kenge, she was already dead. I could not give myself peace. I wanted to know, why did she die?

Why did Victorine die?

- Family pressure for a child
- Fear of being sterile and childless
- Absence of antenatal assistance
- Lack of medicines for prophylaxis and treatment
- Lack of work and gainful employment for women
- Patriarchal family structures
- Women's role confined to child-bearing
- Poverty and lack of essential drugs in the health centre

- Husband was absent – husbands decide about their wives and children
- Nurse was absent – no salary for one year – looking for alternative income
- Doctor was absent – gone to a polio seminar

There was no antenatal check up, no assistance for childbirth and then, during delivery, there was a haemorrhage. Perhaps, in the beginning, it was something small or may be it was placenta previa or placental rupture – we shall never know, because there was no trained obstetrics nurse, not even a trained traditional birth assistant. WHO documents talk of refresher courses for traditional birth assistants and we had such programmes in Nicaragua, but in Congo, such programmes do not exist even on the paper. There was one old traditional birth assistant, who does not know any thing and is without any other training, so we shall never know, what kind of haemorrhage it was. There were so many other things. She was brought late to Kenge because her husband was not at home when the pains came and the child was not coming out. Husbands decide if wives and children can be taken to hospital or not. If husband is not there, you cannot take a woman to the hospital, so this is the first obstacle to reducing maternal mortality, apart from all the other obstacles about access to services, access to drugs, and other things, which are told in WHO books. I know already that in poor communities so many more women die during childbirth than in richer communities. But, the differences I see even between poor countries like Nicaragua and Congo. In Congo, so many more women die, who could have been easily saved.

Most Common Causes of Death Diocese of Kenge

- Malaria
- Tuberculosis
- Sleeping sickness
- AIDS/Sexually transmitted diseases
- Measles
- Meningitis
- During childbirth

The obstacles are many. There are delays in deciding to come to hospital. Even when you decide, there are no means of transport. Often, they carry you in makeshift trolleys made by people. When you reach the hospital, the nurse and the doctor are not there – they have gone to the polio seminar. Polio programme has lot of money and each programme wants its own seminars and activities.

Polio is an important cause of disability, and in the past, it was one of the most important causes of permanent disability. Like the eradication of smallpox was a big victory for medicine, probably eradication of polio will also be a big victory for humanity. So I can understand, why we must invest billions of dollars for polio eradication, but it is not right that in a country with so many

health problems, the public health services are worried only about polio. Similar criticisms have been shared with me by doctors and nurses working in other countries as well. In Congo, our health budget is already minimum, thanks to the structural readjustment programmes and the cost of this never ending war. The amount kept for health services to 50 million Congolese people is just ridiculous and even that budget goes mainly for polio. As if polio is the only problem of public health in Congo, so all the space in the refrigerators is only for polio and there is no space or money for measles vaccines. Other vaccines are no longer important and so, they are not available any more.

To continue with the story of Victorine, I have tried to analyse the reasons of her death. **Family pressure** for a child, her own fear of remaining childless in a patriarchal society of *Baiyaka*, where men decide everything on the lives of women and children. Husbands decide who can be cured, who can go to school, everything. Add to this lack of access to health services. Health services follow the rule of free market. If you have the money, you get the treatment, if not, you are condemned to death. The same free market rules education. If the family does not have the money to pay to the teachers, your child can remain illiterate and stay at home. If you have to choose between male child and female child, the final answer is the same as in so many other countries of the world. Illiteracy means lack of decisional power for women. It means that their role remains confined to reproduction, so the terror of sterility is natural. It is true that there are no family planning services, but Victorine did not even look for such services because family wanted that she produce a child quickly.

There are **no medicines** in the health centre, because these never arrive from the central hospital. When drugs do arrive, these are not the essential drugs, but are other market-driven drugs. Drugs, which are some times prohibited in other countries because they have too many toxic side effects, are still being sold and used in Congo. Vitamin injections are another group of medicines, which come regularly and are used extensively. I feel as if I am fighting against windmills, all my never-ending battles. Useless drugs and injections come to the health centre but not the essential drugs. For Chloroquine resistant malaria we need Quinine but we get injectable Chloroquine. The free-market rules the drug supplies. Every nurse, without any salaries for months, easily transforms into a merchant, willing to sell anything and every thing. All merchants, who come there with their trucks, bringing the medicines, become nurses and sell drugs to the public.

There was **no money** to pay for caesarean section and any way the doctor was not there to operate her. He was in Kenge for a seminar on polio, and as in seminars you get allowances, and if you do not receive salaries all allowances are more important than this woman, who had a haemorrhage but did not have the money to pay for a caesarean section.

So lets come back to try to understand. Poverty, lack of essential drugs, absent husband and absent nurse – he prefers the polio seminar because that is the only way in last twelve months that he would receive any money. What are the common features you see here? Unpaid salaries, war, female illiteracy. In Congo, I do not think that there is that prejudice against women, which is there in some other countries. If free schools were available, I am sure that all female children would also be sent to school. If education was accessible, the women would study as the men do. In a family if

resources are limited and you have to pay for the education, you can be sure that only boys will go to the school and not the girls.

We can also look at the health priorities of Kenge diocese hospital. Look at that list and you can see that among important causes of death or of permanent disability, there is no mention of polio. There are other priorities, much more important, which cause death and most can be prevented, like those from malaria.

Malaria is single most important killer disease in our population. Why do people die of malaria? Because of all those delays. The delay in decision to take the child to health service, even when every one knows that situation of a child is grave, where is the transport? Even if you come to hospital and you have money to pay, who will get assistance first? If you speak French, they will see your child first. If you a rural mother, who speaks only Kiaka and who, stands silently next to her dying child, her child will die before the doctor has the time to come and see her. You die of malaria, because it is almost every where resistant to Chloroquine and it is resistant to Fansidar. It is not yet resistant to Quinine but soon it will also be resistant to Quinine. According to WHO, a woman weighing 50 kg needs to take Quinine 500 mg three times per day for 7 days, 21 tablets. But if you do not have enough money and also because Quinine is so costly, in the end she buys only 12 tablets. Sooner or later, malaria will also become resistant to Quinine. After incomplete treatment, after a few days, the fever comes back. Persons dying from malaria die with heart failure, with pulmonary oedema, with anaemia, which complicate partial, late, irrational and incomplete treatments of malaria.

Second big problem is **tuberculosis**. The ILEP association, DFB provides the anti-tuberculosis drugs to the country, but it is not easy to get these drugs from the capital due to transport problems. But at least, we can provide free drugs and find some local solutions to receive these medicines from the capital.

Everyone knows that I am biased towards our TB patients and as far as possible, we try to reduce their sufferings, while they stay with us for two months of in patient treatment. However, all my efforts to transfer them in the peripheral health centres have been in vain. They do not need to come to Kimbau hospital for this treatment, which can be in a health centre much nearer to their homes. But our health centres do not want them, saying that they “do not have the possibility of “isolating” them and there is risk of infection”. We try to help them with food as well. We make sure that they take their daily dose of medicines. DFB is very efficient and makes sure to supply the drugs to the national level. But if our own health system does not work and our head of health services is busy in polio meetings and other meetings, so our medicine supplies are interrupted. Patients get angry with us and rightly so. We tell them to take the medicines regularly and then we ourselves do not have medicines for regular supply. I call this “iatrogenic abandonment” of treatment. If malaria is the biggest killer of children in our area, then tuberculosis is the biggest killer among adults for us.

Third priority problem for us is the **Sleeping sickness**. Yesterday, I heard that out of 1200 new drugs only 11 are there for tropical diseases. For sleeping sickness we are still using the old and

toxic drug, Assobal. This year, the drug arrived after the expiry date, so what are we supposed to do? Do I send back my patients to their homes to die?

Actually, there is another drug, a derivative of Ornithine called Florinithine, which is effective for sleeping sickness. But it is not produced as it would be useful only for treating some Pygmies in central Africa or for some indigenous rural women in Congo, it is not useful for the sales. Our populations do not understand, as they are more afraid of sleeping sickness than of AIDS, perhaps because if you survive it, sleeping sickness destroys the brain functioning. The drug we use, Assobal is an old drug – it has more than 50 years. About 2% of persons taking Assobal die from its toxicity. Fifty years ago, they did try to study this disease and to find a medicine because at that time there were Belgians who were falling sick from it in their colonies. The whites were at risk, so they studied it and tried to find a remedy – they came to Assobal and every thing stopped there.

Flornithine is not of interest to any one, there is no money from its sale.¹

About **AIDS** I do not want to say much, only because I do not have any personal elements to add to the debate. I admire the battle fought by NGOs and advocacy groups including AIFO, MSF, etc., so that 95% of patients living in developing countries, who do not access to drugs can receive these drugs. AIDS is a problem in Congo as well, worsened by the war. The military is a big risk group but it is difficult to talk to them and to convince them about use of condoms.

AIDS and sexually transmissible diseases are closely related. The war has had an enormous impact on the diffusion of AIDS. I have heard some persons say that if anti-AIDS drugs are supplied to poor countries, they will not take them regularly and just create drug resistance. My experience from TB is completely contrary to this view. If persons are educated about their disease and can have access to drugs, they do not abandon the treatment. However, in a country like Congo, where people talk of high risk of AIDS, you can go all around Kinshasa and you will not find the reagents for controlling the blood for transfusions. So we have to be very careful about blood transfusions and we use them only when it is absolutely life saving, since we do not have any way of checking the safety of our blood. So blood transfusion can be only a last resort, like a child, who is going to die from malaria, but we are never sure if we are not using contaminated blood.

I have put together AIDS and other sexually transmissible diseases because there is an epidemiological double connection between these two. On one hand, in South of the world, the main way of transmission seems to be heterosexual, while in rich countries it seems to be different because of its greater prevalence in homosexuals, because of fragility of anal mucosa. In Africa, syphilis and gonorrhoea are still very big problems. For me these are more urgent problems since I see them every day. Not because they have more un-protected sexual relationships and lesser use of condoms. It is true that condoms are less used, also because they are not easily available in automatic distributors as in Europe. But, there is another aspect, the cultural aspect. It is difficult to tell a couple about condoms, when you know that they are trying to have a child. Even more difficult is the problem of access to drugs. As I am a gynaecologist, I even receive couples from as

¹ Following the campaign in 2001, it has been decided to provide Eflornithine free of cost for five years through WHO.

far as Kinshasa, who are hoping for a child. Often one of the things related to the sterility is complicated gonorrhoea, due to incomplete treatment. They start the treatment but do not complete it because they do not have enough money. So they go the nurse-merchants or to merchant-nurses, who do not know the proper treatment. Thus there is drug-resistant gonorrhoea. 95% of sterile couples that I treat have problems due to incomplete treatment or drug resistant gonorrhoea.

Measles is another problem and here I have to speak once again of the vaccines. Last year, when we had the third campaign of polio vaccination, we were promised that next time, along with polio vaccine, we shall also get measles vaccine. So we had prepared the persons and since there was already an explosion of measles in our area, people were motivated to come for vaccination. When the vaccines came, there was only polio vaccine and no measles vaccine. I felt that they were so cruel, making us believe that it will come. 35,000 persons had come for the vaccination with their children because measles was killing children. But no one is interested in measles. To USA, only polio is interesting because they want to eradicate it even if there is some risk of post-vaccination encephalitis. They first try with the war and throw bombs on our people, then they bomb us with anti-polio vaccines, nothing else counts, and measles does not count.

Meningitis. We had an epidemic of meningitis in 1997, after the massacre in Kenge. Of maternal mortality, I have already spoken.

Most Common Causes of Permanent Disability Diocese of Kenge

- Onchocerciasis
- Leprosy
- Konzo disease
- Diabetes
- Thyroid disorders
- Iatrogenic problems (problems caused by health personnel)
- Road accidents

If we look at the causes of **permanent disability** in our area, polio is not there. Certainly, Congo is one of the last reservoirs of wild polio virus but in countries where breast feeding is prolonged for at least one year, the risk for polio infection below one year is much less. I know that for infection after one year, the risk of paralytic poliomyelitis is much higher. Still there are other important causes of disability.

Onchocerciasis is the most important cause of blindness in our zone, much more than leprosy. When I went to the national office for Onchocerciasis to get some Ivermectin, they told me that I was the last person who asked for this drug and they did not have it. But last time I had been there was in 1998. Why they do not have it? I know that it is distributed free of cost through WHO. I have experience with Ivermectin in Ecuador. But here, the Onchocerciasis programme does not

work. I know that Congo has Onchocerciasis, we have cases in Kimbau but not according to the national office.

The Insia river, which passes below my home, is an important source for Tze-tze fly and other flies. There are so many persons, blind due to Onchocerciasis but no one wants to do any thing for it.

Leprosy is another problem in our area. Fortunately for leprosy, I do not have any problem for drugs since it is guaranteed to me by DFB, while AIFO helps us for other essential drugs. For leprosy the drugs are there but because of the war, it is not easy to go to the national office regularly to take these drugs. Another problem is that of finding petrol for going around and getting all these drugs. Our roads are unimaginable.

We have another cause of permanent disability – the disease of **Konzo**, which causes permanent motor paralysis. In our language “Konzo” means “a little magician”, who can bind the legs of persons, stopping them from moving. Once you have it, you can not walk any more.

A few years ago a team from Sweden came to study this strange disease, which appears each year at the end of dry season, especially in the desert areas in Southwest part of Kimbau. In this zone there are no trees. Environmental desertification is a common problem in our area, also at Kenge, which is all full of sand. In the sand, the only thing that you can grow is Manioc, which adapts to all climates. This manioc plant was imported from Brazil. It is rich in cyanide, a bitter kind of manioc. To remove the cyanide, there are traditional ways like leaving it in running water for five days. But if you are hungry and can not wait for the five days to pass, what do you do? So persons eat it after only two days of cleaning in running water, insufficient to remove all the poison. If you can eat some thing having proteins (like amino acid Cysteine) with it, then its toxicity can be reduced, otherwise you may have acute poisoning with a spinal lesion resulting in spastic paraparesis, which may be irreversible, especially in children and breast-feeding women. The epidemics of Konzo in our area, studies have proved it through analysis of cyanide residues in urine of the patients, are due to cyanide derivatives in manioc. At the end of the dry season as people do not have any thing else to eat, new cases occur. The same toxins also result in chronic calcifying pancreatitis along with diabetes. We have high number of diabetes due to this, even if our people do not normally eat any sugar or sweets. This means that the damage to Pancreas is both to its exocrine and endocrinal functions. So these persons are insulin dependent and you can imagine all the related difficulties, as we are in a place where often there is no electricity and it is not easy to conserve insulin and people are scattered in inaccessible villages.

Let me talk about **iatrogenic permanent disabilities**, that means, disabilities caused by mistakes of the health personnel. These may be due to lack of essential drugs or use of non essential drugs and sometimes abuse or improper use of medicines. For example, Quinine has to be given by mouth or as an intravenous drip but it should not be given as an intramuscular injection as it will cause necrosis. However, often “nurses” can make intramuscular injections of Quinine, some times exactly over the sciatic nerves, some times with non sterile needles. Injections of Quinine over the sciatic nerve made by “merchant-nurses” are one of the important causes of permanent disability in our population.

Even **traffic accidents** are an important cause of deaths and disabilities in our area. I know it sounds absurd to say this, when there is hardly any one with a car or jeep in Kimbau. However, lack of transport also means that there are trucks going around with hundreds of persons hanging out from different sides. Given the state of our roads or non-roads, often they turn topsy-turvy and crash along the side of the roads. Thus every accident kills not just 1-2 persons but 20-30 persons. All those who find themselves on the “wrong” side are crushed underneath, dead or disabled.

Some Temporary Solutions through External Support

- Donations of essential drugs
- Donations of funds for buying petrol for guaranteeing some minimum transport
- Contribution for health personnel's salaries
- Salary for the hospital doctor
- Supply of milk and rice for the patients

We do not have any permanent solutions to our problems. Our aim is to promote development but it is such a slow and fragile process. Our temporary solutions are based on external help like the help we get from AIFO. All other international partners have abandoned us as they say that they do not want to give salaries and free drugs, only AIFO continues to help us. We know that if we go on like this, we are not solving our problems, but tell us what we should do? We need peace, we need roads, and we need a government...

We have started partial cost-recovery programme in our hospital, but if people are so poor, how can be ask them to cover the actual costs of a service or a drug? If AIFO will also stop helping us, we shall be absolutely zero. AIFO provides us with essential drugs, so at least we can make sure that no one should die only because they do not have any money to pay.

It is not that money solves all our problems. Even if you have money to buy petrol, what do you do if they sell it to you adulterated with water, so that you find your vehicle stopped in middle of nowhere?

I agree that the principle of “not paying salaries for government staff” is good but if people have not received salaries for the last 18 months, how are they supposed to live and work? We have an inflation rate of 10,000 times annually. Our money is just paper, without any value while the war makes the inflation run uncontrolled. This temporary solution does not change any thing, we do not become self-sufficient but at least our staff is still here and is willing to work like honest workers, without becoming “nurse-merchants”!

For 9 years, I was the only doctor in Kimbau. Now at least we have been able to get a doctor, a surgeon from Kinshasa to work in the hospital. He is not a missionary and without a private salary, no one will come to work here in this isolated, under-developed rural desert.

Yes, it is temporary solution, but what are we supposed to do? Come have a look at our malnutrition. People die of hunger. In the past, we used to produce so much food that we could sell it in Kinshasa but now we have nothing. With war, destruction, tree-cutting and desertification, every thing is gone. At the end of dry season, people die of hunger and we have nothing to give to the seriously ill patients. We can not buy any thing locally, we must get it from Kinshasa.

Other Measures for Long-term Development

- Hydro-electric project
- Support to training centres and schools
- Differential cost recovery system
- Rationalisation of out-patient, in-patient and emergency services

We have some rays of hope though. Finally the soldiers are going away. They had occupied our staff houses and they used to take our vehicle but now all that is better.

AIFO is helping us with a hydroelectric project, so that hospital and villages can have drinking water and electricity. Our village communities are going to provide the labour. If this can function, perhaps our fortunes will change.

There are projects with schools, technical training institutes and nursing institute, so that students receive notebooks and pencils, etc. The school sells some of these things received from AIFO to pay for school fees for some of the more needy students. One day we shall have our trained technicians, nurses and medical assistants. Perhaps by that time our government will also be more stable to provide them with minimum working conditions.

We are also asking for payment for some services like treatment for sterility, while other services like care for malnourishment and deliveries can be done without payment or very low payment. Perhaps, these rays of hope seem very weak to you, perhaps we do not dare to hope a lot, but it is a beginning.