

QUOTES FROM LEAD CLINICIANS THE EVERY WOMAN STUDY™: LOW- AND MIDDLE-INCOME EDITION

On Access and Affordability:

"We have a few centres that will have access to certain drugs or even in terms of sub-specialists who can treat this – we are limited in terms of resources. So, women will have to travel hundreds of kilometers just to access to that kind of treatment."

Dr. Afrin Fatima Shaffi, Gynecologic Oncology Fellow, Kenya

"We have limited access [to specialized care]. There are only a few centers that have all these facilities [in Kenya] ... It's like a population of 40 to 50 million people coming to these few facilities which are very congested. It's very difficult to handle these large number and the facilities that are treating these [patients], are overwhelmed by the numbers. You're like three doctors seeing 60 patients in one day"

Dr. Afrin Fatima Shaffi, Gynecologic Oncology Fellow, Kenya

"Even when women have realized there is a problem...they may not be able to afford care, because the majority of patients [in Nigeria] pay out of pocket. So, poverty or financial toxicity prevents them even after presentation to afford care."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"Let's assume there is a woman in front of me who has the money to pay out of pocket completely to treat her ovarian cancer. We do not have all of the facilities [in Nigeria], all of the equipment and expertise to treat her."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"In my practice, I saw a lot of patients who came from remote areas, they're very poor and they don't have enough condition to access the internet, the information, as well as the transportation [to the practice] is quite difficult for them. And that is why they usually come to us with very advanced symptoms."

Dr. Ngoc Phan, Gynecological Oncologist, Vietnam

"Nepal does have limitation and shortage of trained human resources/oncologists in the country...our population is 30 million and in the country we have around 30 gynaecologists only."

Dr. Jitendra Pariyar, Gynecological Oncologist, IGCS Mentor, Nepal

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"Nepal happens to have difficult geography, especially high hills and mountains, where travel is a problem."

Dr. Jitendra Pariyar, Gynecological Oncologist, IGCS Mentor, Nepal

"Having a chat with a patient [about genetic testing] and she says, 'What is the point? I only have X amount of money. If I test positive, if I test negative, I can afford to pay for it with that money, [but] I'd rather pay for my children's education. Why use up that box of money when there's no guarantee of a cure?'"

Prof. Dr. Yin Ling Woo, Consultant Gynecologic Oncologist, Malaysia

"We have places in which we don't have any gynecologic oncologists [and where] there are no resources for doing a good practice of gynecologic oncology. Blood bank, good pathology, laparoscopy access, imaging... all these are lacking in most of the places. So, the person has to travel to those places... The patient doesn't have the money for traveling long distances in my country."

Dr. René Pareja, Gynecologic Oncologist, Colombia

"[In the state sector] we only have targeted treatment with compassionate programs, professional programs or if it's for research or clinical trials."

Dr. Tracey Adams, Gyne-Oncologist, South Africa & Co-Chair Every Woman Study™: Low- and Middle-Income Edition

"We ended up using other chemotherapy that's not normally used internationally [for ovarian cancer]. But because we are limited [and] in an effort to try and improve the quality of life before we say we have nothing left."

Dr. Tracey Adams, Gyne-Oncologist, South Africa & Co-Chair Every Woman Study™: Low- and Middle-Income Edition

"Better cancer care services [in Bangladesh] are limited to some specialist centers only."

Prof. Dr. Shahana Pervin, Professor of Gynecologic Oncology, National Institute of Cancer Research and Hospital, Bangladesh.

"[In Bangladesh, most] hospitals give their treatment from the government fund, but sometimes they do not get all the costs covered. So, in those cases, we have given some money to our patients. Even our own doctors have donated blood, and some even donated drugs and everything."

Prof. Dr. Shahana Pervin, Professor of Gynecologic Oncology, National Institute of Cancer Research and Hospital, Bangladesh.



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On Awareness/Education:

"Some of the challenges we experience here [in Kenya], are very low levels of education, people are not able to understand that they're sick."

Dr. Afrin Fatima Shaffi, Gynecologic Oncology Fellow, Kenya

"Awareness [in Nigeria] is really very poor. Women, including educated women, are not aware about what ovarian cancer is and its symptomatology, its risk factors, how it can be detected or managed."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"I think it would be better if there were better education in the country."

Dr. Carlos Alberto Chirinos, Gyne-Oncologist, Peru

"South Africa is a very diverse country, in terms of eleven languages, so language may be a barrier in terms of communicating...often we have interpreters. So how the information is interpreted is maybe a challenge on how they understand it."

Dr. Tracey Adams, Gyne-Oncologist, South Africa & Co-Chair Every Woman Study™: Low- and Middle-Income Edition

On Cultural Factors

"In some communities, the men are basically the ones who make the decision, and the elders. Basically a woman cannot come to a facility if she does not get consent from the husband or the elders."

Dr. Afrin Fatima Shaffi, Gynecologic Oncology Fellow, Kenya

"There may be cultural barriers to even presenting at the health facility. This is because women are highly dependent on their male partners here in Nigeria, and they will need, one, permission to even go to the hospital. Secondly, they need the funds and finances to go to the hospital, because the majority of women here are not empowered to make decisions regarding their own health"

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"Women [in Vietnam] are very hesitant to share their experience and so, the time for them from their first symptoms to the first meeting with gynecologic oncologists [are] longer, and so, that's why they normally come to the hospital with a really advanced stage."

Dr. Ngoc Phan, Gynecological Oncologist, Vietnam

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"Sacrifice is a bit part of personalities of Vietnamese women, their sacrifice their life for their families, for housework – and they don't care much about themselves."

Dr. Ngoc Phan, Gynecological Oncologist, Vietnam

"We are a patriarchal society [in Nepal], so [women] don't have this decision making-role...She lets other family members to make appropriate decisions."

Dr. Jitendra Pariyar, Gynecological Oncologist, IGCS Mentor, Nepal

"I think one of the things that's quite strong here [in Malaysia]...is that the family or the extended family has a big role to play in the care of patients. So very often patients don't decide themselves, they will see whether their children are there, how it fits into the children's schedule, and transport cost."

Prof. Dr. Yin Ling Woo, Consultant Gynecologic Oncologist, Malaysia

"[Women in Malaysia] don't want to be a burden to their families."

Prof. Dr. Yin Ling Woo, Consultant Gynecologic Oncologist, Malaysia

"In small and rural cities [in Peru], [patients] have the habit to seek treatment with shamans or 'the doctor' from the town or the city. So many times we have patients that had been with shamans for many months. So the patients, when they came to the hospital, they came with a big tumor, and it is difficult to treat in that case."

Dr. Carlos Alberto Chirinos, Gyne-Oncologist, Peru

"I've had women coming to speak to me saying there is something inside, it moves from here to there and there, which is a problem [and is interpreted as] some kind of witchcraft."

Dr. Tracey Adams, Gyne-Oncologist, South Africa & Co-Chair Every Woman Study™: Low- and Middle-Income Edition

"The main cause of the obstacles [to diagnosis and treatment] or what are we are facing is the poverty of the patients. There's illiteracy, there are superstitions, the religious barriers, and communication problems are some of the most important problems."

Prof. Dr. Shahana Pervin, Professor of Gynecologic Oncology, National Institute of Cancer Research and Hospital, Bangladesh.



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"[Most] of our patients are dependent on either their husbands or they're dependent on their sons, because... they are illiterate. So they are dependent and if their husbands or their sons do not take them [to] the hospital, they do not reach the hospital."

Prof. Dr. Shahana Pervin, Professor of Gynecologic Oncology, National Institute of Cancer Research and Hospital, Bangladesh.

"There is a widespread belief is that cancers are caused by spirits (jinns) and should be treated spiritually. The traditional healers vehemently warn afflicted patients against hospital presentation, injections, and surgery. As such, some of these women die without ever presenting to hospital"

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

On What is Needed:

"We need policymakers, we need stakeholders, we need government to be on board with us... We need to increase more training. We need to train people to be able to treat these cancers and we also need to create awareness and advise women on health seeking behaviour."

Dr. Afrin Fatima Shaffi, Gynecologic Oncology Fellow, Kenya

"I think there is a lot of work to be done in terms of advocacy – in terms of changing the narrative. It is very challenging to change cultural beliefs."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"I think if we can come together as a huge partnership or collaboration, to see how we can do this on the media, the news media, the print media, to social media – talking to women going into the communities, meeting people who speak their own language, who look like them, who dress like them, talk to them, will make them believe in whatever we are telling them."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"I think one of the things we can do moving forward is what we are doing now – talking about it."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"You must think about mainstreaming, think about how could perhaps upskill or coordinate with the regional hospitals, regional sites to try and support ovarian cancer management in a smaller hospital."

Prof. Dr. Yin Ling Woo, Consultant Gynecologic Oncologist, Malaysia



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"We need more gynecological oncologists. We need more resources. The strategy is on the paper, but it is not in the cities. We have few institutions, few gynecological oncologists. So, without resources and without institutions, it's very difficult to ensure a good treatment."

Dr. Carlos Alberto Chirinos, Gyne-Oncologist, Peru

"We have some delays, and this is one of the first challenges to overcome – to decrease the waiting time [to be] seen by the specialist."

Dr. René Pareja, Gynecologic Oncologist, Colombia

"We have no centralized care. We have no proper surgical training."

Dr. René Pareja, Gynecologic Oncologist, Colombia

"With education comes understanding and knowledge."

Dr. Tracey Adams, Gyne-Oncologist, South Africa & Co-Chair Every Woman Study™: Low- and Middle-Income Edition

"The older women, they listen more to the radio...radio still works in South Africa – especially for those who don't have access to television. Also, remember there may be women in South Africa who can't read, but they can listen, so some form of reading is not a necessity [to] provide access to more."

Dr. Tracey Adams, Gyne-Oncologist, South Africa & Co-Chair Every Woman Study™: Low- and Middle-Income Edition

"I think the Every Woman Study™ is a start. You can get some data because there's no data... I don't think there is a recognition that ovarian cancer is or should be a priority currently, and the only way you can get there is to show [local authorities, governments, and clinicians] the numbers."

Dr. Tracey Adams, Gyne-Oncologist, South Africa & Co-Chair Every Woman Study™: Low- and Middle-Income Edition

"If we have a cancer registry and if we provide awareness to our patients, then we can treat our patients."

Prof. Dr. Shahana Pervin, Professor of Gynecologic Oncology, National Institute of Cancer Research and Hospital, Bangladesh.



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On Women Being Left Behind

"If you investigate it, there are so many women who are not really diagnosed and just end up dying in the small facilities and we're not able to really pin down that this death is because of ovarian cancer."

Dr. Afrin Fatima Shaffi, Gynecologic Oncology Fellow, Kenya

"We cannot offer to give the same care to these women with the same disease condition. It is largely dependent on what these women can afford. That will determine what we can do for them."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"I can't cure all of them, but to help them dignify the process to give them the respect to just support them."

Prof. Dr. Yin Ling Woo, Consultant Gynecologic Oncologist, Malaysia

"I think sometimes ovarian cancer is neglected. So our cervical cancer case numbers in South Africa are higher, but our case fatality ratio in ovarian cancer is higher... The numbers that we often have refers to women who do present – there may be women who die in rural areas without a diagnosis."

Dr. Tracey Adams, Gyne-Oncologist, South Africa & Co-Chair Every Woman Study™: Low- and Middle-Income Edition

"After the surgery the girl... received only one cycle of chemotherapy. After that she went to her house, but she has nobody to bring her back again."

Prof. Dr. Shahana Pervin, Professor of Gynecologic Oncology, National Institute of Cancer Research and Hospital, Bangladesh.

On Data

"It is not every case that gets to be recorded in the [Nigerian] cancer registry. So individual institutions that perform the pathologic diagnosis keep records, most of these records are still analog – and that's on paper rather than a digital record."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

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"We know that most of these policy formulations cannot be done without appropriate data. That's correct data and record keeping... Record keeping is usually a challenge, we have tried to conduct multicenter research, and we keep having missing data of women who have had ovarian cancer. And as such, you cannot actually [determine] the true burden of the disease in your institution or in the country as a whole."

Dr. Aisha Mustapha, Consultant Obstetrician Gynecologist, Nigeria

"Nepal needs its own data...so that we can explain our situation to organizations like yours, and our authorities, hospital authorities and government as well, that it will be important for formulating guidelines [and] setting up priorities."

Dr. Jitendra Pariyar, Gynecological Oncologist, IGCS Mentor, Nepal

"Sometimes, when patients don't access care, they may be classified as someone who's dying of old age. So our classification for death [in Malaysia] is still not very tight from the ICD standards."

Prof. Dr. Yin Ling Woo, Consultant Gynecologic Oncologist, Malaysia

"I know one thing I'm very aware of what the perception of a physician like myself will be very different from the perception of a patient. And I can only tell you how I perceive it and hopefully the interviews from the Every Woman Study™ would bring about a patient perspective. I certainly know from other studies, we do have quite different perspectives, and that's why this Study is so important."

Prof. Dr. Yin Ling Woo, Consultant Gynecologic Oncologist, Malaysia

"We don't have a proper cancer registry. We have cities with cancer registries, but [a national] registry doesn't exist in [Colombia]. So our simulations on disease burden are based on GLOBOCAN but we don't know exactly our numbers."

Dr. René Pareja, Gynecologic Oncologist, Colombia

"We have no cancer registry – we have not yet established a national cancer registry. It is just our hospital, our government hospital, the National Cancer Institute, that has the data."

Prof. Dr. Shahana Pervin, Professor of Gynecologic Oncology, National Institute of Cancer Research and Hospital, Bangladesh.



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