



Dr Fatima Cardoso interview – January 2019

Interviewer: One of the things that's kind of difficult as a person who's got this diagnosis, you get pitched into a situation where it's suddenly lots of decisions. It's stuff that you don't know about. It's confusing. It's an emotional time. It's distressing. I guess I wanted to start with: what kind of relationship do you think that we should expect to have with our oncologist?

Dr Cardoso: Well, I think always, from my perspective as an oncologist that treats advanced breast cancer patients, I always think that we are a team, and we have the same goal, and we are fighting the same thing, from different perspectives, of course. Your situation as a patient has no comparison with our situation as healthcare providers, but we are on your side. We are on your team, and we are doing anything in our power to defeat it the best way we can – this disease, for as long as we can. In every relationship, for me one thing that is crucial is to be truthful. So, no lies.

Unless you as a patient – and everybody is different, right – you don't want to know everything, and then in that situation you should tell that to your oncologist and say, look – knowing everything stresses me – just tell me just on a need-to-know basis. You're being truthful also, and then your oncologist also knows how much should she or he tell you, and how much should you be involved in the decision. So, in principle it's always better if you are involved, but I've had some patients that along the way said, look – I trust you, and it's stressing me out to have to think about all these decisions, so please just tell me what I need to do – explain to me the side effects, what I can do to improve, and I don't want to know more for now. I respect that. So, I think the most important thing is to be truthful, and to speak openly, and to know that we are on the same side.

Interviewer: I guess one thing that many of us feel a little shy about is working out where we can go in the path of drugs and trials, and things like that. So, I guess as an oncologist, how can we, as patients, kind of – is it important to keep asking questions, and questioning sometimes about how about this drug, or what trials are there – what can possibly help me?

Dr Cardoso: I think you should question. It's your life, so you have every right to question. Again, I think openness is the most important thing, and you can tell your oncologist, look – I am someone who likes to know everything, and I'm always reading, so I hope you don't mind that I ask you some questions - maybe they are silly questions, but it's my life and I'm worried. I think that a good oncologist will perfectly understand that. That's fine to question and to ask what about this and what about other things.

It is also perfectly correct, and you have the right to do it – to have a second opinion, and an oncologist should not be upset with that. I know that some of my colleagues get upset, because they feel that you are questioning them, but that's a bad attitude, and just because they are having a bad attitude, it doesn't mean you don't have the right to do it. Everyone has the right to have a second opinion. If it tells you exactly the same as your oncologist, it increases your trust in your oncologist. If it tells you something different, it opens up other possibilities, so I think it's a right that you have, and that it's also good.

Interviewer: One of the things that many of us think about is the role of complementary therapies in our treatments, and sometimes it seems that some oncologists are not as open as this to others; what's your opinion about a more holistic treatment, and the role of complementary therapy?

Dr Cardoso: We also look at that in the guidelines. If you read the guidelines, you will find some information about some complementary treatments that they've actually proven to be good. They were tested and trialed and they were proven to be good. There are others that are proven to be bad. So, I think that more and more there is an openness of clinicians for complementary therapy. What is very crucial is that you tell your oncologist what you are doing, because some of these complementary treatments, they seem harmless but they are not. They may change the efficacy of the other treatment that you are doing. There are interactions. For example, there are many interactions with Tamoxifen - some interactions with some chemotherapies, so we need to know what you are taking to make sure that there are no bad effects on other treatments that you may be doing.

So, the most important thing is again, to be open, and you should know that probably about 80 per cent of cancer patients use some form of complementary therapy. So, our perspective is it's not something that we should be against. It's something that may even help control some side effects. So, if you have a look at the guidelines, you will find there for example, acupuncture has been proven good for nausea, for hot flashes, and can be used for that. Also, sometimes it helps in the joint pain that some treatment gives, but there are other supplement type of things that have a lot of interactions with the usual medication, and that should not be taken. Then, there are a couple of things that actually harm you, because they harm the liver.

Interviewer: So, what are the things that harm you?

Dr Cardoso: I don't want to say by heart, because I might say the wrong things, but they are written in the guidelines. They are written by name, and says, this one you should not take, and that one you should not take.

Interviewer: So, what are the ones that are proven to be useful?

Dr Cardoso: Well, acupuncture is useful. It's probably one of the most useful things. Then, things that are based on ginseng are good to fight fatigue. Some of the supplements, for example magnesium, are also very helpful to fight the fatigue, and also some of the muscular pain. I don't know any more by heart.

Interviewer: Vitamin C?

Dr Cardoso: Vitamin C is one of those things that there has been no benefit proven, but there is also no harm. So, if you want to do it, you can do it, but it is not proven to be beneficial. For example, vitamin D is one that you should have in normal levels, because it helps your bone health a lot.

Interviewer: One woman wrote in asking about statins; your opinion about are they safe to take?

Dr Cardoso: They're to control lipids.

Interviewer: I believe so; is that sort of to do with the cholesterol – statins?

Dr Cardoso: Yeah. So, there are indications to do it, if you have the alteration of your cholesterol – of your other triglycerides, but in terms of if you should take it to fight cancer; no, there is no reason to do it, unless you have altered cholesterol.

Interviewer: So, moving on to sort of a broader question now. I know you've been here for a number of days now, and you've read our report, and so know what kind of a tough situation we're in; what has helped in other countries in improving treatment and care for everyone with Stage 4?

Dr Cardoso: I had also a very productive meeting with the oncologists here, and there are a couple of things that they will try to do. So, there is some information coming out of the report that needs to be better clarified. So, it seems like about 20 per cent of patients don't ever reach oncology. So, there is something in the access; entering the system and be able to be seen by an oncologist on time. So, they said they were going to go really in depth trying to understand what the barriers are for people to get to an oncologist quickly enough. Then, we also discussed a lot about writing guidelines, so that everybody is treated not according to what an individual physician thinks, but according to what's the best care available.

So, they will probably take the ABC guidelines and they will write a New Zealand version of them. I will try to work with them on that. Then, when we say write a New Zealand version, what we mean is there is a series of guidelines that you can implement in New Zealand. There's no problem about it. There are others, because they are more related with certain treatment, that if the treatments are not available you cannot implement a guideline. So, you need to think of other alternatives in the absence of those treatments. So, that's the goal of adopting some guidelines. The third part is of course to make a case towards your reimbursement body about certain types of therapies that you must have access to, with a priority list. So, you cannot ask everything, because it would have an enormous economic impact, but you can have a priority list, and fight with them for access.

Interviewer: So, I know that ABC has a goal of doubling life expectancy; what are the particular kinds of strategies that you've got to do that? What are the steps to get us there?

Dr Cardoso: Well, every country must analyse where things are not going so well, and where things can be improved, because for you to double the survival, you cannot just go for one strategy; there is a combination of strategies. So, I already told you some; people must reach care quickly, so that they are still in a situation where they can be treated. Also, in the report, it was seen that the number of treatments that patients receive here in New Zealand is much reduced – an average of two, when usually we can treat someone with five or six lines of treatment. So, that's also something important to try to find out why it's not happening, and make it happen. Then, obviously also fight for access to the treatments that are still not available here. So, in every country it would be different. For example, let's take a country like Germany; they have access to everything. For them to double the survival, you need to invest a lot in research as well – on development of new treatments, because we always need new treatments if we still are not able to cure the disease with the treatments we have. So, it's a combination of things. Some will be more important in some countries. Others will be important in other countries, but a combination of strategy.

Interviewer: I guess one question I had is about returning to some drugs that you've had in the past, and maybe coming back around to them. For example, Tamoxifen. Can you tell me a little bit about that? I'm interested that you can come back around to them.

Dr Cardoso: Yes, you can. So, for the type of cancer that we call the hormonal dependent cancer, very often we give several lines of endocrine therapy, and then we need to go for chemotherapy. Just because we go for chemotherapy, it doesn't mean that we must stay in the chemotherapy; we can go back to something that was used several years ago, and use it again. Why? The biology of the tumour is always changing a little bit, so once the tumour has not seen a treatment for a long period of time, it may – to say in a simplistic way; it may have 'forgotten' about that treatment and not be so resistant as it was previously. So, it's always a possibility to go back to those treatments.

Interviewer: I have to say, someone like me whose oncologist is saying you're kind of at the end of the endocrine treatment now, and chemotherapy is the way to go, that is a relief to hear, that there can be some return, and have a go at a drug you've had in the past. So, I think lots of women will be interested in that. That's good to hear. I wanted to just talk a little bit about Ibrance, and just you probably know this, but the expense of this drug here in New Zealand is crazy. For example; I'm a woman taking this drug at the moment, so if I buy it in New Zealand it's just under \$6000 a month.

So, some of us have become medical refugees, and we go up to Malaysia and buy the drug there. So, if we go up there, the cost is just under \$2500 a month. So, of course, it's a crazy situation to be in, and very distressing, and it means that for the women and some men in this community, it's awful. Some can do it – some can't, in terms of taking this drug and funding it. So, with all of that background, I guess one question from one of the ladies was, can you tell us a little bit about the relative benefits of Ibrance as a first main treatment, compared to after hormones or chemo?

Dr Cardoso: I don't like to talk about commercial names, so I prefer to talk about that class of agent that is called CDK 4/6 inhibitor. So, cyclin inhibitors. So, palbociclib which is the chemical name of Ibrance is just an example. There are others; ribociclib and abemaciclib. So, they are all very similar. It's a little bit like the aromatase inhibitors; you have three, and they are all very similar. So, here it's the same. Palbociclib was the first one to reach the market, but it's not the only one.

Interviewer: Sorry to interrupt, but before you go a little further; if you take one of those drugs and it stops working, is it worth trying the other two as well, or –

Dr Cardoso: No.

Interviewer: Okay.

Dr Cardoso: No, it's like a class of agents. So, at least I'm telling you no now, because it's the current knowledge. We still don't have strong data to tell you that there is no benefit at all in, for example, coming back to it later. We don't know, because these treatments are still very recent and we don't know everything about them. For the moment, there is no evidence that we should do that. So, in terms of those agents, there are a lot of unknown or unanswered questions. So, for example, we don't know if it is better to give it as a first line, or to give it as a second line. We still

don't know how to choose. We still also don't know the true impact of these treatments in survival. We don't have very strong data about the survival impact; do they really prolong life, or are they just helping to control the disease? But even if they are just helping control the disease, they are good drugs. Why? Overall, they are well tolerated.

They have some side effects, but they are not the worst of drugs in terms of taking them, and tolerating the side effects. They do help control the disease for a long time, without having to go for chemotherapy. So, it's also a gain to delay the use of chemotherapy. If you tell me, for example, here in New Zealand they're looking into the drugs that are missing or that you don't have access, if palbociclib would be my top priority, it would not. It would be my second priority, because there is another group of drugs that our patients here don't have access to, that truly impact on survival. It's not for your type of cancer, but it's for the HER2 positive type of cancer.

There, we see a true impact and substantial increase of survival with the use of those anti-HER2 therapies, and what I understood from here is that - a lot of things are missing in that field here in New Zealand. It's only one patient out of four, but for those patients, these treatments truly improve survival. For example, with the report that's here in New Zealand, the median survival for HER2 positive is about 13 months, while in other countries, these patients live very often five year, six years - even more. So, you see it goes from one year to five or six or seven. So, it's a huge difference.

Interviewer: What is that group of drugs called that you're talking about here?

Dr Cardoso: The name of the sub-type of breast cancer is HER2. HER2 is the name of the gene and a protein, and it's the crucial driver of that cancer.

Interviewer: The group of drugs that you're talking about there?

Dr Cardoso: Anti-HER2. So, it's those who have a very difficult name like trastuzumab, pertuzumab, T-DM1. They have those difficult names, but overall this class of agents are the ones that block this receptor.

Interviewer: Are there particular places around the world, or countries who have managed to put reforms in where access to drugs for Stage 4 people has vastly improved? What would be a place that New Zealand could look to as a good example of a country that is on track?

Dr Cardoso: The access to these expensive drugs is a problem all over the world. So, New Zealand is unfortunately not alone in this problem, and countries are sometimes even getting together to fight together, because a small country alone doesn't have a lot of power, but if you are grouped with other countries then you get more negotiation power, you see? So, for example, let's say that New Zealand forms a group with Australia and other Asia-Pacific countries, then you can negotiate together with the companies to try to make the drug less expensive. There is no magic solution. Unfortunately, we all struggle with these prices, and we are all trying to fight also for the prices to come down. In some of these treatments, or the trastuzumab that I told you about, there are now biosimilars. So, biosimilars are generics of complex drugs. If the biosimilar has been approved by the FDA or by the EMA, then you can trust that biosimilar, and it's about 30 per cent less expensive than the original drug. So, that's also a good solution, and we just have to keep on fighting for the drug to have a more accessible price, because these are becoming totally crazy.

Interviewer: I guess a lot of us in this situation hold on very tight to stories of people in a Stage 4 situation who experience remission, and some kind of remarkable recovery - what's your comment on this? Studying people who are in this fortunate situation; can we possibly learn anything from these kinds of isolated cases that are rare, but they exist?

Dr Cardoso: They do exist. There is currently a project ongoing – it's called the Exceptional Responders Project, where we are collecting the biological materials of blood and tumour, from these exceptional responders – these patients, and analysing all this to try to understand if there is some special characteristic of the tumour or of the person that justifies the very good response, or to see if there's something we could then implement in other cases. So, we are looking into that and really trying to understand what drives, in some situations, an excellent response.

Interviewer: I'm also interested in your response as an oncologist. I guess, as a patient I think maybe there are factors that can't be measured, that we could bring into the situation, for example, an attitude that we're living with a chronic disease – it's an attitude of living, not dying, and kind of x-factor things. What do you think about other factors that patients could think about to live well, and possibly get some benefits from that? What do you see with women or some men that you've dealt with, that they can bring to the table to help?

Dr Cardoso: There are also some research projects looking into the impact of more, let's call them psychological aspects – so, the way that you face the disease. A lot of studies have shown that the way that you face the disease, or hide the disease if you want, is also important in your recovery, instead of just giving up, or being sad all the time, that you keep living your life. Sometimes people say: 'I have cancer but cancer does not have me.' So, okay, I have to live with this disease, but I'm not going to let the disease control my entire life. This is a very good and positive attitude. We do know that having a positive attitude – I'm trying to not use the word 'fighting' attitude, because I've heard from some patients that they don't really like the war analogy...

Interviewer: Yes, the battle terminology.

Dr Cardoso: Yeah, so I'm trying to move away from that, but I think you understand what I mean; those who do fight – who don't give up, and don't let the disease take over their entire life - that is also very important in terms of allowing you to live better, the time that you have.

Interviewer: Yeah. I see. I think that's pretty much all my questions; is there anything else you'd like to say that I haven't asked you? I was very much interested in talking from a patient's perspective because we're all just kind of getting on with it, and having you here is really kind of very hopeful for us, that on a global scale, things might be turning around.

Dr Cardoso: Yes, maybe just a message to all of you that when I started this, I wrote a small editorial saying you were our heroes, and you were the ones showing us the most important lessons in life, but for a long time you have been some forgotten heroes. But you're not forgotten anymore, and we are really doing our best to try to find a much better solution, and if not possible a cure, at least that we'd really transform this into a chronic disease with which you can live decades and not just years. We are fighting hard for you, and we'll keep on doing that. The second message is that there are very – as you know – you already know Metavivors, but there are also other groups of

patients all over the world that are trying to develop support tools, and helping each other the best way they can.

So, use the good things about technology that you can get together, even being very far away. One place you can get together – get more information – know what we are doing around the world is through the ABC Global Alliance, and you can just go to the website and have access to all the tools that we put there. Sometimes we also have some webinars, discussing some particular topics that may be of interest, and you don't have to attend live, because due to your difference it might be in the middle of the night, for example, but we record them, and they stay online, and you can just go there and listen. So, try to make the most of the things that we try to put there available for you, and don't give up.

Interviewer: Thank you for talking to me, and thank you for the work that you're doing, and for coming out to New Zealand and talking to us all here.

Dr Cardoso: You're welcome. Thank you.