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#404: Getting cancer care to better reflect patients' lived experience

VOICEOVER

This is Up Close, the research talk show from the University of Melbourne, Australia.

ANDI HORVATH

The diagnosis and treatment of cancer since the mid twentieth century have vastly improved with our growing understanding of cell biology and the genetics of cancer in tandem with the development of better technologies, but patient healthcare is more than physical diagnosis and treatment. We now know that cancer patients' health outcomes are also influenced by a complexity of cognitive and emotional experiences over the entire illness, and part of that psychological dynamic can be found in the relationship between patient and clinician. I'm Dr Andi Horvath, and our guest on Up Close today has long been investigating the health outcomes and survival rates of cancer patients, looking not only to the medical treatment modalities, but also to the impact of lived experiences and clinical communications. So how does a cancer patient's experience of illness help to inform their treatment, and how does it interact with what the medical experts bring?

Joining us is oncologist Dr Lidia Schapira who is the director of the Cancer Survivorship Program at the Stanford Cancer Institute. She's also Associate Professor of Medicine at the Stanford School of Medicine. She's an active clinician who specialises in the care of women with breast cancer. Her research is focused on improving quality of life for people with cancer and cancer survivors. Meanwhile, she's also an educator running workshops and developing programs in how people communicate in the clinical setting. Dr Schapira is in Melbourne to take part in the Inaugural Research Conference of the Victorian Comprehensive Cancer Centre. Lidia, welcome.

LIDIA SCHAPIRA

It's great to be with you. Thank you so much for having me.

ANDI HORVATH

Lidia, people living with cancer have various types of cancer treatments, but how has cancer care of these patients evolved?

LIDIA SCHAPIRA

It has really changed over time. I got very interested in this early on when I was the doctor of a patient who was an anthropologist, and she taught me, at that time very early on in my career, to really think about lived experience from a very different point of view that was not doctor centric. So I was very fortunate from a very early time in my career to start thinking more broadly, and I'm absolutely delighted to have been part of this evolution towards giving patients and family caregivers access not only to specialists and cancer care, but also to people who come with training in how to bear illness, how to take charge when one is faced with a very difficult or uncertain diagnosis. So I think one of the things that we need to think about is that cancer care has really evolved into truly a team sport with members of the team coming from various disciplines that address mental health issues, that address family issues, that address lifestyle issues.

So now being diagnosed with cancer and being in the care of a team of experts really looks at multiple dimensions of life, including what we have termed now the lived experience with the patient being more active and with a care plan that takes into consideration from the moment of diagnosis all the multiple needs, and anticipates what those needs are going to be over time.

ANDI HORVATH

Take us through the cancer journey because there are different stages of cancer treatment and, of course, cancer care. As a cancer clinician, you're the central touch point for these patients over the course of their battle with cancer, and this can go on for a long time, even years. So give us an overview of the cancer journey and tell us about how cancer patient care reflects the changes in the illness along the way.

LIDIA SCHAPIRA

So we could talk about this for days and we can walk through different scenarios, but let me try to answer your question. We all know when cancer is diagnosed, so there is a very clear beginning. What we often don't know is where that journey will take us or where that journey will take a patient. Somebody may be diagnosed feeling very well because they had an abnormal screening test, and all of a sudden they're deposited into this unwanted land of cancer where they may be facing treatment for a year or even more and an uncertain prognosis. Other people may come to be diagnosed with cancer because they're feeling ill and perhaps being diagnosed and getting the treatment provides a sense of immediate relief. So there are many different entry points. There are different prognoses associated with the stage and the type of cancer. Even if you are diagnosed at an early stage sometimes the biological aggressiveness of the cancer may provide a very uncertain future.

So this is a funnel a lot of people are deposited in, this cancer treatment land, and what happens is determined a lot by all of those factors. That said, there are distinctive phases of the cancer journey: the diagnosis; the treatment; and then the time that we now call survivorship, which is the time out of active cancer treatment, sometimes with an uncertain future, sometimes with a very, very good expectation of living out one's full life without having it shortened. But along the way, people get different treatments, often many different teams. I mean, there are some patients - for instance, patients who have cancer of the ovary - for whom the gynaecological surgeon may take care of everything including administering chemotherapy. But for a woman diagnosed with breast cancer, she's likely going to meet a surgeon, a radiation oncologist, a medical oncologist, perhaps a psychologist, so there may be many more people involved in the team. So there are different points.

Sometimes the care may feel fragmented. It's typically very complex, involves several treatment modalities and takes place over not just a few weeks but often many months, up to a year depending on what kind of treatment one has. There may be patients who have a hematologic malignancy and face very complex treatments including even a marrow transplant which, again, is a very intensive procedure. So there are distinct phases of the journey. There are different points of entry into cancer, but what's common to everybody is that it's not as if you can just deposit your cancer for treatment and pick it up later. It involves the whole person. So it resets one's ideas of one's own future. It often resets or shifts relationships, so there are lots of changes at a very personal level that accompany a diagnosis of cancer, and that's even without addressing the fact that our cancer treatments are often very toxic.

When we think of somebody we know or love who's had cancer, we immediately think of a bald head and we think about all of the other unfortunate toxicities that come with many of the cancer treatments. I feel in the last couple of decades that one of the greatest advances and breakthroughs in cancer treatment is not just that we've become more precise about treating the cancer with far better treatments and better outcomes but also we now have supportive interventions that help deal with some of these very unpleasant or toxic side effects of treatments, so overall what we're looking for is smarter and kinder treatments. We need to build alongside that the supportive services that will help each individual to bear this as well as they can, to be engaged, to become more active, to advocate for themselves. That's the other piece of the story where we have a patient who is engaged who's able to say, these are my symptoms, to communicate those effectively and clearly and have a clinician respond to them.

That's where we can also see real progress. So when we talk about psychological interventions, it's body and mind together. It's having patients who are able to say, help me, and this is what I need help with, and then to have that patient active and able to self manage as well as possible. We now have good data that those kinds of interventions which in medicine we think of as patient reported outcomes can actually impact on health outcomes. So we have data emerging over the last decade that when you avail yourself of all of these procedures you actually may live better

and longer.

ANDI HORVATH

Lidia, it's been a long held belief that good patient rapport and bedside manner have a positive effect on health outcomes, but this hasn't been stringently tested until now. You've been involved in the research that actually measures this. Tell us about that research.

LIDIA SCHAPIRA

I've been a long champion of good communication. I wish I can tell you I have great level 1 evidence from a randomised control trial - I do not - that better communication makes patients live longer. But what we do have from the work of colleagues including Ethan Basch who presented this at the ASCO meeting in June 2017 in Chicago is data showing that when patients are able to report their symptoms through the patient reported outcome instruments and that is immediately brought to the attentions of clinicians that they're able to have those symptoms managed, and that translates into longer survivals. Why? It may be that toxicities are averted. It may be that by bringing those concerns to the attention of the treating clinicians they're able to make adjustments that allow patients to get the right treatment at the right time and so they're able to complete their cancer treatment.

So I think the lesson learned there through Ethan's work and through the work of many others, including those who are working in palliative care, is that access and good clear communication not only provides improvement in lived experience, but actually translates into measurable health outcome, such as extended survival.

ANDI HORVATH

You're advocating a patient driven care as opposed to an expert driven care. So how does that actually work in the clinical setting?

LIDIA SCHAPIRA

It's interesting. We teach our medical students from the beginning that the meeting between the doctor and the patient is a meeting of experts, and this comes from some of the anthropological work of Professor Kleinman at Harvard where he's often said that we should really ask patients, tell me what you think started the illness. Tell me how you think the illness can be treated. We teach this to our medical students, and we take this very seriously, and then what happens is we get caught into the busyness perhaps of practice and when we become experts in a disease we forget a little bit that the patient really is not just a pathology report but actually somebody with distinct beliefs and orientations towards science or towards other practices. So we may stray a little bit and we talk and now in oncology we're all for bringing that idea of that equality back so that we say, fine, we're experts in disease. We should inform patients. We should create decision aides. We should offer to share

responsibility in the decision-making. But sometimes we pay more lip service to that and we actually end up deciding more than the patients would like us to.

So, one of the examples when this goes well is when the clinician asks the patient, how much information do you want, and how much do you want to be involved in deciding, for instance, what kind of surgery to have or so on, and then tailors the conversation to what the patient has just said, and everybody is very happy. But sometimes there's situations where patients come in with a request or a demand for treatment that doesn't really conform to the evidence, and often that leaves us, as experts, a bit perplexed. One example is what we've seen in the world of breast cancer which is where I feel very comfortable clinically. In recent years in the United States in the last decade we've seen an increase in demands, especially among young women, to have more surgery than they strictly need.

So there has been a grassroots movement looking for more bilateral mastectomies when we know that that will not necessarily improve their survival if they've been diagnosed with an early stage breast cancer and we, as the medical experts, have been trying to - scratching our heads wondering we've tried so hard over decades to show through research that you don't need to do all of these complex surgeries, and yet patients want more than what we think they need. How do we respond? I think that requires a different attitude there and perhaps the answer is that for many of these women they view the more extensive surgery as perhaps freedom from worry. Perhaps that's worth their peace of mind and so I've seen a lot of negotiation from the experts who say, maybe you don't need the surgery, to the patients who came in and demand more than perhaps is absolutely necessary. That is presenting new challenges to those of us who are interested in good patient/physician communication.

ANDI HORVATH

That was actually my next question is how do the two compete?

LIDIA SCHAPIRA

Well, I think that this is an area that makes going to work exciting for all of us every day. I may know what the data shows in terms of treating breast cancer. I may have guidelines or have participated even in creating some guidelines, but when I'm meeting a person I need to listen to what it is that she brings with her and then use my expertise to guide her. I've been in situations in the clinic where the first thing the patient said is, I want to have as much surgery as possible, and all it took from me is to look her in the eye and say, why? What do you hope to gain by doing that? Then when she starts to talk then we can have a conversation and perhaps I can bring in some data to help her reframe her thinking, but without good conversations and without listening to patients, you can't really think of having better health outcomes.

ANDI HORVATH

I'm Andi Horvath. On Up Close we're joined by Stanford oncology clinician and researcher Dr Lidia Schapira to talk about comprehensive cancer care. So how do we actually arrive at personalised care for the individual patient?

LIDIA SCHAPIRA

Right. So we are making a lot of progress these days in what we call precision medicine and precision cancer medicine. So what that really means is we're getting better at interrogating tumours to give up their secrets of what's driving their growth and then trying to match that to the available drugs. That's making us very happy and that we're creating more opportunities and options for treatment that will hopefully minimise some of the collateral damage of cancer treatments and will lead to more efficient and better outcomes. What I would love to see accompany that is the same approach to the person who's bearing this tumour so that we would take into consideration all of the aspects that are worrying them, all of their physical, emotional and existential concerns and also the toxicities of cancer and deliver a package of supportive services that addresses it so they can address the illness with as much calm and confidence as they're able and that, I believe, will also impact on their ultimate outcomes.

ANDI HORVATH

Give us a case study of how the patient's experience of illness intersects with the process of care. I know you've done a lot of work in the breast cancer area.

LIDIA SCHAPIRA

So let's take, for instance, a woman who's in her early fifties and is diagnosed with breast cancer and up until that point she's been a confident mother of two and she has a great job and life is fine and then everything starts to fall apart for her a little bit and she finds herself very anxious. So she's faced her cancer. She's had her surgery, her chemotherapy, her radiation. She's now taking some endocrine therapy because her tumour was hormonally sensitive and she expects to do this for a number of years, but she finds herself very worried about every physical symptom. So she has abdominal pain and she fears that she has metastases to her liver. She has a headache, she fears she has brain metastases. She aches and she fears she all of a sudden has cancer that has spread to her bones. This is not an uncommon scenario. So this is a young woman who has a good prognosis but is now suffering from anxiety and distress.

She fears her cancer will come back and these thoughts are so intrusive that they dampen her sense of joy every day. So we need to attend to that. So she may need a specialised assessment. She could benefit from some forms of therapy through some very short interventions that psychologists love and have tested and have been shown to be incredibly helpful in the setting called cognitive behavioural therapies. She may benefit from that. She may benefit from exercise to help perhaps reduce some of her stress. She may benefit from joining a support group where she

listens to other patients who've gone through this and they can provide information and support. So I can think of three, four, five, six different interventions that have already been tested and have been shown to be effective that can help this hypothetical patient to get over some of these very distressing symptoms and greatly improve her quality of life.

ANDI HORVATH

How do you persuade your fellow physicians to actually take this model of cancer care on board?

LIDIA SCHAPIRA

The best way to have the conversation is to talk about results. So if we can show that patients are more satisfied, that patients feel better about things, that it leads to better outcomes in terms of quality of life, and sometimes even we have data on survival, not for every situation, that's the way to have the conversation. It's not so much do it because you'll feel better or do it because it's important, but this is what your patients need and this is what you're going to be judged on. So I think the way in is to really address the fact that this is something they need to pay attention to. Any surgeon taking a patient into the operating room wants that patient to be happy with the results. It's in that surgeon's best interest to really feel that that patient trusts them and that their goals are completely aligned.

ANDI HORVATH

So, Lidia, is the patient then almost in a consumer role?

LIDIA SCHAPIRA

I resisted that term for many years, but I think it works because if the patient walks into the door feeling informed, and that's one of the reasons why I spend a lot of time designing information that's out in the public domain. If the patient is informed, if the patient brings somebody else with him or her, there are two people who are activated and asking questions. What we know from research is the more questions that get asked, the more information is exchanged. So if the patient says to the doctor, are there other forms of treatment for this disease, are there other kinds of surgery that I should think about? Tell me and let's think about what my options really are and let's think about outcomes together. If the patient is calm, informed, and if the relationship is set up to be collaborative, it's more likely that the solutions presented will be what we call high value and fit with best standards of care and also please patients.

So patients do have options sometimes to even ask for another opinion or even a third opinion, so I would say that if somebody feels that no information was exchanged and only one approach was handed down, as if this came from a tablet from God, then perhaps they need to look for other options or a deeper conversation.

ANDI HORVATH

Now, it's not just the clinicians but oncology nurses have a role here in this emerging model of cancer care. Expand on that for us, too.

LIDIA SCHAPIRA

Oncology nurses are absolutely indispensable to any model of care. They sit with patients. They often have a lot of time - I was actually going to say the luxury of time - because it allows them to really develop rapport and relationship. They have an incredible set of skills - physical skills such as inserting cannulas for treatment. They're experts in doing assessments, so they're able to not just get an impression but really in a very scientific way to collect data to see how people are doing. They're the experts in managing common symptoms. So oncology nurses are the key point of providing context for the patient, validating their concerns, eliciting their worries, enumerating their symptoms, then also are perfectly situated to provide the right information, to contact the clinicians if new prescriptions need to be written to address some of those symptoms, and to even initiate referrals if they feel that the patient may be, for instance, physically well but emotionally floundering.

Oncology nurses play a key and pivotal role. They are coaches. They are listeners. They deliver treatment. They manage symptoms and they often are perhaps the person that the patient loves the most in the team. So it's important to remember that and to bring in the perspective and the voice and the expertise of nurses into the overall care plan.

ANDI HORVATH

Today on Up Close we're talking about improving cancer patients' lived experience and health outcomes with oncologist, Dr Lidia Schapira from Stanford University. I'm Andi Horvath. So, Lidia, what's not working in cancer care at the moment in 2017?

LIDIA SCHAPIRA

A few things. I think that perhaps the fact that the experience is very fragmented and there's often a lack of communication along the different clinicians on the team, and sometimes that is also accompanied by a lack of good and clear communication to the patient and to the caregivers of patients, family members. So problems in communication and problems in care coordination. Where I work in the US, patients often drive long distances to get their cancer care. They may have a GP or a primary care doctor in the community who feels left out of this. So sometimes if the patients find it very hard to know who to call if they're experiencing a symptom, is it the radiation oncologist? Is it their GP or primary care doctor? Is it the medical oncologist? Is it the nurse on the team? So care coordination is a problem. Breakdown in communication. Sometimes patients are not properly informed.

I think this has been a long running theme in cancer care that the patients may feel overwhelmed when they're listening to all possible side effects that could come with

their treatment, but they don't quite know how to manage all the different pieces or how to do those assessments in their own home. So I think the main problems are perhaps lack of support and lack of information and lack of care coordination.

ANDI HORVATH

There are a lot of supportive services before, during and after cancer patient care, like counselling and rehab. How do we need to rethink those?

LIDIA SCHAPIRA

We need to get in there as soon as we can with supportive services and we need to personalise them and do this with the same rigour we do for typing tumours or doing pathology exams or genomic sequencing on tumours. So people come with different needs and I think that finding the right interventions or pointing people in the right direction so they can solve their own problems is key. You're absolutely right. There have been so many studies showing that there are many interventions that are helpful in perhaps treating fatigue and reducing the sense of isolation. There are wonderful sites that provide information to the public that are available through the web. What we need to do is really try to figure out from the beginning what the needs are, not just of patients but family caregivers. This is also an interesting area of emerging research and that is that if we don't attend to the needs of the caregivers what we often find is that they impact on the patient's quality of life.

So, what we would need to do is map out all of the resources available in our geographic area wherever we happen to live or practice, and then map out all the resources that were available on the web in an increasingly interconnected and global society. Sit with a patient, figure out what their questions are, what their needs are, and try to figure out what is the best way of giving them in person services or providing long distance services, coaching interventions over the phone or in person, information, access to rehab or even prehab. So, for instance, if somebody's going to get a chemotherapy drug that's likely going to affect their sense of hearing or their sense of balance and they already come into this with perhaps an advanced age or some form of neuropathy that even predates the cancer diagnosis and we're going to give them a drug that could make it worse, we better send them to see a physical therapist soon. If?

ANDI HORVATH

This is what you mean by prehab.

LIDIA SCHAPIRA

It's exactly right. So prehab instead of waiting for that same patient to come and say, I fell down the stairs yesterday, in which case you would need to do an intervention through rehabilitation to try to restore function. So I guess where I'm going at is as much as possible if we can prevent loss of function, we would be doing far better

than trying to restore function once it's lost. It's almost like thinking about physical conditioning. It takes a lot of effort to be in good shape, especially if you're not very young, but it's very easy to get out of shape and to get deconditioned. So if we could think along those lines both physically and emotionally to say, what does it take this person to bear their treatment, to get through their illness, and anticipate that? That's in the basket of what I would call anticipatory interventions or prehab if it comes to a physical toxicity.

ANDI HORVATH

Following on from prehab, does there need to be more focus on cancer prevention? So tell us a little bit about perhaps preventative measures there.

LIDIA SCHAPIRA

It's so interesting, again, over the last couple of decades. I think all of the oncologists have really realised that it is our job not just to treat cancer, but to dedicate ourselves professionally, individually, collectively to prevention of cancer. The best conversation you and I can have over cancer is to think of it as something in the past and we can find other things we can talk about that have to do with health. So we all should commit ourselves to prevention, and there are things that even treating oncologists like myself can do and, for instance, if a patient or a family member smokes we should address smoking cessation with them because smoking is really an incredible cancer promoter in patients and families in our societies. So we need to think about interventions that help reduce risk of cancer recurrence once cancer has been diagnosed, but we also need to think about prevention and that may be on a one to one counselling against obesity and smoking, for proper nutrition in favour of exercise, all of these factors that we now know - these lifestyle factors that contribute to cancer. Also really, I would say, on a global basis I think all of us should become activists in campaigns to reduce the burden of cancer and suffering from cancer worldwide.

ANDI HORVATH

So, Lidia, how does your work also contribute to or inform end of life or palliative cancer care?

LIDIA SCHAPIRA

I think we should all be very realistic about the fact that despite great breakthroughs in cancer a large number of patients will die of their disease, and we need to be prepared to talk about that very frankly, to prepare and counsel patients. I started a lot of this work in communication thinking about ways of talking about death and dying with patients and the patient that I started the story with, my friend the anthropologist, died before her fortieth birthday of metastatic breast cancer. So it was a very personal journey. I've had many, many such conversations over the years with patients and it's always very difficult to say goodbye, and you hope you can do this

with sincere and genuine affection and knowing who they are as a person by the time that this happens, especially if you've cared for somebody for many years. I think as a society we need to be more open about talking about death and dying.

We need to educate our medical students, our young trainees, but we also need to educate educators and legislators so that we become as a society more open to the fact that there are some times when science just doesn't have the tools to perhaps really change the course of a disease. So cancer is still a leading cause of death in many of our societies, and the period that precedes the death of the patient from cancer is often one of complex symptoms, usually a burden of symptoms that affects not only the patient but families. So I think that through exquisite attention to those symptoms, expert management of the symptoms, multidisciplinary care including experts in palliation, open communication and hopefully some solidarity among members of the community. That's what I mean by changing the culture so we're more accepting of the fact that there are people who are dying of illness and we should all do what we can to reduce their suffering.

ANDI HORVATH

How will the current evolution of new technologies, particularly in the digital realm, help us work with improving health outcomes and lived experiences for cancer patients?

LIDIA SCHAPIRA

I could make you laugh by telling you that you should imagine having a small empathetic robot sitting in your living room reminding you to take your medication, reminding you to take 2000 steps because you've been sitting for three hours. So if we look into the future we can think of technology as coming into our homes in all sorts of ways that perhaps we hadn't thought about before, but we could also think about, again, a digitally savvy society using smartphones to help, again, with reminders to take medication, reminders to call our cancer nurse to report on whether or not we're having nausea the third day after chemotherapy so we might get some advice. So I think that technology holds the promise of connecting us and if we use it wisely it could help, for instance, your well intentioned cousin who lives 1000 kilometres away and has a background in nursing to weigh in and talk directly to you and your cancer team if you so allow.

So, I think technology can do a lot for us and we should not view technology as necessarily cold or impersonal. Technology can be whatever we want it to be and can actually provide access to our clinicians, our experts, our larger community of supporters who may not be in our immediate physical neighbourhood but may deeply care and send messages of support that can feel sustaining at a time of illness or crisis.

ANDI HORVATH

A lot of people access Dr Google, but in actual fact there is better information out there.

LIDIA SCHAPIRA

I've spent a lot of time working on this idea of how better to inform the public. Each major cancer centre in the United States, for instance, has its own patient information portal. I happen to work with the American Society of Clinical Oncology which is a non-profit and our website for the public is called cancer.net. We have about four million visitors per month. A lot of the traffic comes from overseas - about half - a lot of it from Australia. We offer expert, vetted information about cancer care. So we're pro-science, expert oriented. We also have information about coping with cancer, navigating the challenges of cancer care. We also talk about end of life. We're not afraid to talk about any of these subjects. That's just one site. There's a site that US oncologists use a lot called UpToDate, which provides information for clinicians. They also have a portal for patients. So the same information that experts access is written in an understandable level for patients.

So these are just two ways of having somebody - perhaps not the patient but somebody in the patient's team - the patient may be overwhelmed and when emotions surge, cognition fails. But somebody on the patient's team could be delegated to do some research and come up with some questions that then can be asked of the experts during the consultation.

ANDI HORVATH

This has been a fascinating discussion about building research that's informed by clinical cancer care from bedside to benchtop and back again. Thank you, Lidia.

LIDIA SCHAPIRA

You're very welcome. It was lovely to be with you.

ANDI HORVATH

We've been speaking about caring for people living with cancer and rethinking clinical models for improving patients' lived experience and health outcomes with Stanford oncologist Dr Lidia Schapira. You'll find a full transcript and more info on this and all our episodes on the Up Close website. Up Close is a production of the University of Melbourne, Australia. This episode was recorded on 19 September 2017. Producer was Eric van Bommel with audio engineering by Gavin Nebauer. By the way, you may want to check out another of our podcasts, Eavesdrop on Experts, which features stories of inspiration and insight in conversation with researchers. I'm Andi Horvath. Cheers.

VOICEOVER

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