THE LACNETS PODCAST

With Mona Mojtahedzadeh, MD
Released on November 15, 2022

Lisa Yen

Welcome to the LACNETS podcast. I'm your host, Lisa Yen. I'm the LACNETS, Director of Programs and Outreach as well as a caregiver and advocate for my husband who is living with NET. In each podcast episode we talk to a NET expert who answers your top 10 questions.

This podcast is for educational purposes only and does not constitute medical advice. Please discuss your questions and concerns with your physician.

Welcome to the LACNETS Podcast. I'm really excited to introduce our guest for today. Dr. Mona Mojtahedzadeh from UCLA Simms/Mann Center for Integrative Oncology. Dr. Mona, as she is known to her patients and colleagues, trained to become a medical doctor in Tehran, and she worked as a general practitioner to the underserved population in a health and urgent care clinic in Iran. And then she worked as a physician consultant, for the United Nations High Commissioner for Refugees office in Tehran, and also served as a clinician caring for asylum seekers in the International Organization for Migration.

Dr. Mona then completed her psychiatry training at Texas Tech University and Loma Linda University, and then completed a fellowship in consultant liaison psychiatry at USC, LA County. All this is so impressive, and Dr. Mona was previously at City of Hope, where she was assistant professor in the Department of supportive care medicine. Which is well known to us, as Dr. Banerjee who also works with us, also works at City of Hope with supportive care medicine.

Dr. Mona now works at the Simms/Mann-UCLA Center for integrative oncology, where she practices whole person care for people living with cancer, also known as psycho-oncology. And we're really grateful that Dr. Mona is in this field as she works with people living with cancer all throughout their cancer trajectory and lives. And of course, that includes the neuroendocrine tumor population.

A fun fact about Dr. Mona is that she enjoys music, art, poetry, and not only does she paint and enjoy reading poetry, she writes her poetry in Farsi. Welcome Dr. Mona, we're so excited to have you. And feel free to introduce yourself and [tell us] a little bit about yourself.

Dr. Mona Mojtahedzadeh

Thank you, Lisa, so much. Well, you know, the honor really goes to you and your team. It is so incredible to be here. I feel really as a small member, I want you all know what great deal you're doing. I can see with a little encounter we already had, although virtually, the enthusiasm, the perseverance and all the flexibility. Also, that you are able to show with regards to this job that you love, you know, helping people. And I'm sure your audience love it, too.

So, I'm really honored to be here saying that. And then, I do take credit for writing poems. I've written like three or four, so, or maybe a little more when I was younger. But I like to take ownership on that I'm a poet, even though I don't know if it is already appropriate to say that. Thank you so much. I'm excited to be here.

Lisa Yen

How fun that you write poetry. And we're really excited to have you. So, as we get started, there were a couple of big words that came up in the introduction, "psycho-oncology" and also, "consultation liaison psychiatry," would you explain what those fields are before we jump into our 10 questions?

Dr. Mona Mojtahedzadeh

So, psycho-oncology is really like a subspecialty of psychiatry. And in its term is actually an extension to the consult liaison psychiatry fellowship. So, you wouldn't imagine [there] to be many, right, with the academic training. While there may be general psychiatrists, who can be of great help to cancer population, by virtue of passion and practice. And so, anybody as a psychiatrist can really work in this area, once they show the passion, gained the experience. But by its term psycho-oncology, it's a fellowship added to the four years of psychiatry training that was started back in 1977, by Dr. Jimmie Holland, at Memorial Sloan Kettering Cancer Center, and has been ongoing in a couple of places in the United States. And it's, it’s a wonderful training.

Lisa Yen

Well, we're glad that you're trained in this field. And this might be a good time to transition. The first question just kind of taking a step backward, who might seek psychiatrists and how does one go about finding a psychiatrist that's right for him or her?

Dr. Mona Mojtahedzadeh

Lisa, so as a member, you know, a patient's multidisciplinary team the psychiatrists would ideally be another layer to the patient's other psychosocial services, right? So not every patient with cancer or major medical illnesses would necessarily benefit from a psychiatrist, but being already medical doctors and with their medical background, there are situations that psychiatrists can help with better understanding of complicated mood shifts.

And so to answer your question, when you have the stress or emotional suffering, whether it's depression, anxiety, or other rapid mood shifts, you know, behavioral changes, thought changes, even if a direct response to a trigger, we are here trying to talk and tailor it to our population of audience, but so even if it's a response to the trigger directly. But if has been lengthened, or just out of control, feels

out of control, and it's been impacting, in a sense, areas of functioning, major areas of functioning, say, social interactions, work, education, or personal functioning, taking care of yourself, those are major areas that you would definitely benefit from seeing a psychiatrist.

Lisa Yen

I can imagine many of us would benefit for sure.

Dr. Mona Mojtahedzadeh

Exactly, yeah. Imagine we just came out of a pandemic, we all have gone through, you know, periods and come out, right? What we want to do is to remove stigma to empower people to ask for help. A lot of patients who come to us have never seen a psychiatrist, nor would they even imagine if they would see a psychiatrist in their life. So that's already a great deal of strength to come to us to ask for help and to want to work towards getting better.

Lisa Yen

I really liked that point that you made Dr. Mona, the asking for help takes courage.

Dr. Mona Mojtahedzadeh

It does. It is a manifestation of strength. And I learned that from our patients. A lot of things that I'm going to say here is really what I've learned from the patients. Either I've learned from them firsthand, you know, I hear, I read about them, or, you know, I ponder upon, read upon or hear about it, because of them. It's really, you know, for me inspiring to work in this field. And so, what we're just talking about, this is what I learned from the patients, I read it and then I see it, you know?

Lisa Yen

The patients are the inspiration. And you said something also that many people have never seen a psychiatrist. I mean, many people diagnosed with NET have never really been in the hospital or had other medical illnesses. So, all of it is such a shock compounded. So, you know, I'm wondering with the next question, I know we touched a little bit on what is psycho-oncology, I'm wondering how is psycho-oncology different from general psychiatrists, and if someone is living with NET and looking for psychiatrists, should they look for someone trained in psycho-oncology?

Dr. Mona Mojtahedzadeh

So, as I said, because we have such wonderful, great psychiatry colleagues that are interested, passionate about the field of psycho-oncology, and have great deal of experience, we do count on them a lot. And it's just as I said, it's a limited number of people who practice in psycho-oncology, but overall, or have been trained, per se. But overall, we generally advocate for patients to continue with their own psychiatrist during these times, should they have already had one, and they established bonds with already.

So that's also another, another tool that they already have a psychiatrist for a number of years. So, for the one who has someone already, sometimes psychologist can be like a second opinion or like a consultant here. But for someone who doesn't have anyone, has been diagnosed with cancer, and is seeking help in this area, has been you know, recommended to see [a] psychiatrist, which is very

common, as we just talked about, we have multiple ways for patients to find one. Usually, depending on where they're receiving their cancer treatment, whether it is in a major cancer center or just within the community, their oncologist, the primary oncologist or their PCP (Primary Care Physician).

So, our family practitioners are very good at knowing who to refer these patients to, right? So that's a very great way of finding your resources. Or the patient can be referred to the therapist or their social worker or patient advocates. And once they have the conversation, and they realize that patient would benefit from [a] psychiatrist, psycho-oncology, so they can make referrals too. There are great resources through the Cancer Support Community. And we have direct lines and help lines for that we can share but really, they can offer, you know, a lot of resources, as you're aware, for groups, counseling, peer support, financial support, but also resources for psychiatry within the patient's area, or the American Cancer Society. Sometimes patients will on their own, decide to seek one given their previous experiences and or histories or peer recommendations.

Lisa Yen

Yeah, many resources here. So, asking our provider or PCP, the social worker, and then as you mentioned, the nonprofits, the cancer support community, American Cancer Society, or just a referral.

Dr. Mona Mojtahedzadeh

Or the American Psychosocial Oncology Society, they also have a helpline.

Lisa Yen

Ah, that's good to know as well. Thank you. So, our third question is how do you determine if symptoms such as depression, anxiety, mood swings or fatigue are symptoms caused by the neuroendocrine cancer or not?

Dr. Mona Mojtahedzadeh

Thank you, Lisa, such a great question. You know, cancer overall being a major public health problem, and as the death rate decreases, and population ages, so overall, people living with cancer [are] growing, and the psychosocial impact and quality of life has been becoming more and more important, right?

So, I'm trying to say that to answer your question, first, it is important to differentiate between is it appropriate sadness versus clinical depression. And you know, this diagnosis, I mean, intuitively would say it's very distressing and can cause a dysphoric mood, anxiety, insomnia for a variety of reasons.

So, getting to depression, if we're talking about this is like more depression. And clinically, we're thinking of depression. You want to look for etiologies, there are multiple etiologies. And you're very correct in the sense that cancer or NET by itself can cause symptoms of depression by virtue of biologically other than psychological impact that we'll discuss. But biologically, also, they would show inflammation, or increase in stress can increase cortisol production. So oxidative stress, and all of that can cause symptoms of depression in patients impacted by cancer, but also there are, I feel like another layer to your question was that there might be symptoms that NET produces that, not necessarily depression, but those symptoms can overlap with symptoms of depression.

And so, you want to be able to differentiate. Is it from the cancer? Or is it from depression? Or do I need to treat the depression? In these circumstances, there are multiple ways that psychiatrists can utilize usually looking at, generally speaking, you want to look at risk factors that the patient had, you know, history of depression. Is the support system there? What are the coping styles they are using? What is the cancer burden? What is the stage of cancer, location, all of that. But also, overall, we do have various approaches, looking into the symptoms, trying to understand whether this is really clinical depression, there is an approach that you want to remove the symptoms that are more neurovegetative, and only focus on mood symptoms.

But that approach, which is called exclusive approach, has been found to really miss people who might be suffering from depression and not treating them. So, the more accepted approach here is the inclusive approach, meaning a diagnostic approach that really takes into account all these neurovegetative symptoms with various weights. And it's most sensitive and most reliable that providers can use for their clinical judgment regarding somatic symptoms in patients impacted by cancer.

So, you take into account the risk factors, as we discussed, but you also try to have an overall inclusive approach. It is important to not undertreat. And if not properly treated, depression, specifically in its full-blown clinical form, cannot only increase the chances for poor quality of life, which were there and all that, but also increasing suffering and aggravating the physical distress, and negatively impacting survival, both biologically, and also by reducing desire to adhere to treatment, to screening procedures. This is all great things to get into if we had more time. But overall, I want to try to emphasize that it is important you see the depression there, you want to look into the etiologies, and you want to address that.

Lisa Yen

Wow, it sounds so rich and complex. And your point too, it's important not to undertreat, right, because it can lead to more suffering, physical, emotional, all of it. And I imagine not just for the person suffering, but also their loved one. So, thank you for that.

Dr. Mona Mojtahedzadeh

It's difficult of course. And it is difficult because, as I said, not a lot of people do have a psychiatrist or think they would ever have, right? And so this is a change by itself, like okay, I'm impacted by this illness, and now I'm going to also see a psychiatrist, like I don't need one, right? But there are barriers to a proper psychiatric treatment. Part of it is really what you said, like difficulty distinguishing between whether is it cancer symptoms, is it symptoms of depression?

So, this has already established a barrier to treatment, if it is a depression, uncertainty about the effectiveness of the treatment of the psychosocial interventions. There is also fear of the side effects, the stigma is there. So yes, and also there is perceived impact on expressing negativity on the course of cancer, like this perceived concept that you don't want to express it because you want to show positivity, it might be a sign of negativism that can be applied on your cancer course.

Lisa Yen

Yeah, like you said, we wanted to destigmatize that, and then hopefully affect a change so that the person can thrive. You know, let me take a step backwards. I know we're talking a lot about, well, your field psychiatry, and people might see a psychologist who also treats depression. So, this is kind of a more basic question. What is the difference between a psychologist and psychiatrist, and someone seeing a psychologist for depression? How do they know if they need to see a psychiatrist?

Dr. Mona Mojtahedzadeh

So, while psychiatrists always appreciate different psychotherapeutic modalities, so important role in helping people, but really, the visits are limited and the experience is limited. But psychologists will have a vast majority of experience, and this is a huge, important aspect of people's mental well-being.

And so, psychologists and psychiatrists work hand-in-hand. This is the best approach that they can work both hand-in-hand when the patient is in need. And it's expressing symptoms that require to be addressed. A lot of times, patients would see a psychologist, and they're given great tools that, you know, they're improved already, their symptoms are improved. And they do not even need to see a psychiatrist. So, they either continue with our psychologists to maintain it, you know, with a reduced frequency or decide to return if their symptoms returned. And then psychiatrist can be accessible if again, psychology [is] not effective, the functionality, as we discussed, is still deteriorating. And our psychologist colleagues are wonderful in distinguishing these symptoms and referring patients accurately to us.

Lisa Yen

Yeah, thank you for that. So really, it can work hand-in-hand. And so perhaps that next question, building on what you were saying earlier ,about managing and treating symptoms, this question comes up a lot, right? Is it safe for NET patients, particularly those with high levels of serotonin, to take antidepressants, such as SSRIs, that they might be concerned with increased levels of serotonin?

Dr. Mona Mojtahedzadeh

Yes, great question. To answer this question. First, let's think of what is NET and then we will go into a couple of most recent and largest studies in this area. So, you know that is a neuroendocrine tumor distributed from the neuroendocrine cells, distributed throughout the body. I was just reading between 1973 to 2012, the tumor of neuroendocrine cells, which we call neuroendocrine tumor has been growing, both because of the rising incidence, but also earlier detection better treatments.

So again here's, reflecting back to what we were talking in the beginning, it is important like the now the quality of life becomes important, now the psychosocial, psychological impact becomes important. So NET tumors can be like functioning or non-functioning, meaning they can produce hormones and peptides and other substances, approximately like 30% of NETs, you know, mainly in those in the GI the gastrointestinal colon, the pancreas, and then bronchial and the lungs, produce substances and those that produce substances, which is mostly serotonin are called carcinoid syndrome.

So, it's not a lot of patients with NET that do have the carcinoid syndrome. But carcinoid syndrome is really the clinical expression of hormones that are excessively produced and most apparently, we're talking about serotonin, which is the most common produced here and can produce symptoms of

flushing, palpitations, diarrhea, dizziness, shortness of breath, reducing blood pressure and in most advanced cases can have carcinoid crisis, right?

So, I'm not an oncologist. I don't want to really get into these deep, but overall, we're trying to say that this serotonin that is being produced in carcinoid syndrome, is it substance important for mood, for anxiety, for sexual desire, appetite, sleep, body temperature, and it is made out of amino acid tryptophan.

So, we have this whole tryptophan in our body, but during a carcinoid syndrome episode, this tryptophan, like about 60% of it is consumed with tumor cells for the peripheral synthesis of serotonin. Which will cause reduction of that amino acid in our central nervous systems. So, what would you imagine as outcome of this process that we just said? There are three possibilities that may arise. One is that the deficiency of tryptophan overall, right? Tryptophan is not only necessary for synthesis of serotonin but also melatonin, Vitamin B3.

The other possibility is the deficiency of serotonin within the central nervous system. So, there is a fact that the peripheral serotonin cannot pass through the blood brain barriers to enter the central nervous system. But tryptophan can pass. So if tryptophan is reduced, is utilized in the periphery, no matter how much serotonin is produced in the periphery, it cannot pass through the blood brain barrier to be there utilizing the central nervous system. So, we will place them in…, patients can face deficiency and serotonin in their central nervous system, which then can cause those symptoms of depression, anxiety, and poor impulse control. The possibilities, potential possibility, that can arise from divisions in serotonin.

So, the other possibility is the increased serotonin within our GI system, right? It is being excreted now in enormous amounts in the GI system, which will increase GI motility, and all those symptoms of carcinoid syndrome that we described. So having said all this, it is proven based on studies that people with neuroendocrine tumors, especially overall cancer patients, have higher chances of depression. But especially if neuroendocrine tumors have carcinoid syndrome will have more chance of depression, anxiety, impulse control, aggression, [the] possibility of all of this can be there potentially when there is carcinoid syndrome.

So, SSRIs are the first line antidepressants used for depression. And they are generally safe. So, despite their safe and common use in cancer patients, but they were first called into question in 1997 by case reports describe the unmasking of carcinoid syndrome from the use of SSRIs. And then later on there was another study in 2005, that described another case, in a NET patient who developed severe diarrhea from the SSRI use. Another study in 2008, in which actually the authors recommended avoiding SSRIs in NET patients that are impacted by NET.

So, around the same time, those small case series was being published describing the SSRI use in five patients with NET that none of whom had any adverse outcome. And now I want to come to more recent, we're talking about 2020, 2021 studies. There were great systematic reviews that were done. And one of them in 2021 was a review of existing literature about psychiatric disorders associated with NETs. And also, it addresses the safety of psychiatric drugs in these patients from all the articles that they were able to gather from 1965 to 2021. And this all encompass 3,319 patients, 351 of which had carcinoid syndrome.

But this is not a small number given overall scarcity of NET, right? And specifically, the carcinoid syndrome ones. Yes. So, it reported higher rates of depression 50% compared to the 15 to 20% of general population, especially in a NET patient with carcinoid syndrome, higher rates of moderate to severe anxiety, and other psychiatric very little, possible like 20 only with impulse control, very only three with psychosis. So those were like very scarce, but we're really trying to more focus on depression and anxiety that were more prominent. So that was reported that the numbers are significantly more than general population, but also about safety.

From the 52 patients in the Dana Farber Cancer Institute that were treated with SSRIs, between 2003 to 2016, less than 10% had mild exacerbation of carcinoid syndrome and between 92 patients that got SSRI from 2008 to 2015, none had developed carcinoid syndrome. Overall, yes, the rate of psychiatric symptoms in patients with NET is significantly higher than in control groups. And I'm trying to emphasize here that it deserves lower threshold for referral to mental health professionals—psychologists, psychiatrists, by the use of measurement tools or clinical judgment, whatever method clinicians and providers are more comfortable with and experienced in.

So, the conclusion from that systematic review was that SSRI use in patients with NET is safe and free of any significant adverse outcomes. But, of course, further studies were required. And also, there was another possibility that patients with NET can also, or may also, benefit from other psychotropic or medication that psychiatrists give to address specific areas like sleep, [and] appetite.

Another systematic review (I don't want to go too much into numbers in this one) 2021, it just has a lot of okay, seven case reports and three large case series overall 161 cases. 72 of which had carcinoid syndrome. And overall, out of all these numbers, four of the single case reports none of the patients with NET had precipitation of carcinoid syndrome, meaning that they didn't have that, and then it developed, so none. But, in those who already had carcinoid syndrome, four did report exacerbation of the symptoms from the, you know case represent, and six from the large case series. So overall 10 out of 161. But three of these patients did not even discontinue their SSRIs even though they did report their exacerbation.

So, it's possible that either the symptoms were controlled with dose reduction, or just weren't severe enough to begin with that the patient decided to stop the medication. You know, we always need to use our clinical judgment and assess risk benefit. So, it was interesting that somatostatin analogs, like octreotide, were also proven to buffer against some of those SSRI mediated carcinoid syndromes. But that was very limited studies around it.

Overall, there is a huge potential for a systematic undertreatment of depression in patients with carcinoid syndrome. So even if sufficient evidence exists, which do not exist, but if it did exist, this could be problematic, especially troublesome given high rates of depression and poor quality of life that we just described. And their impacts on cancer course and everything, quality of life of patients, so but still, it's recommended to have close monitoring for diarrhea and flushing when you start the SSRI, which usually if they want to present, they start after first dose. And what are the recommendations if the patients experience exacerbation of symptoms? It's proven that it's not life threatening, right? So, it's all about patient tolerance.

So, dose reduction, reduction in the dose of the medication, or initiation or escalation of the somatostatin analog, or discontinuing the whole medication or changing to another medication. And

thankfully, we have all of these great resources and tools other than medication that can really help our patients. I mean, that's a beautiful discussion that we can get into some time.

Lisa Yen

No, thank you so much for that really thoughtful and very thorough explanation. I mean, you gave us a whole literature review, which is probably the first time most people have heard much of this information and data. So really appreciate that.

And, I mean, really big takeaways, again, this theme of depression. Depression, anxiety, but depression really being undertreated in the population, and having a low threshold for referral, and treating however the individual needs. So generally, it seems like it's safe is what you're saying, and tailoring it to the patient, because they may need another drug. And you want to monitor for their tolerance. And overall, it's about quality of life. So, what they need. So, thank you for that.

Dr. Mona Mojtahedzadeh

Thank you.

Lisa Yen

I guess the next question would be then, if someone living with NET struggles with depression, how do you approach that? What is your approach? And how do you determine the best treatment option for them?

Dr. Mona Mojtahedzadeh

So, it's all about patient preference. And as I said, patients, a lot of times haven't gone to a psychiatrist or haven't even imagined going to one. So, I do not want the idea of medication to be like the first on the table. I mean, they might not want to take it or they might really benefit from the other tools like psychotherapy and a lot of other resources that we have, and do not even need the medication. But so, respecting the patient's wishes and finding the right treatment or resource for them to benefit from tailored to that specific patient's needs, the individual's needs. Never, as I said, underestimate the benefit of therapy, and I'm sure no psychiatrists would.

So, we will try to employ as much as feasible therapeutic interventions during our visitations, which are limited, but the best would be really to refer to the right therapist for the patient that could see them on the right frequency, and the right length of time with a great deal of experience that they have additional, much more than we do in their areas.

And then if the patient, I try to really have this conversation with our clients, on what is their preferred method. I mean, a lot of the patients come to us and are very a fan of, you know, herbal medication, or whatever natural and sometimes there are things that they're trying already. I'd never prescribe herbal medication for depression, but there are things that they're trying already that is working and it's not interfering with any of their treatments, whether cancer treatments or nothing. And so, you know, it's working, it's working. It's funny here that I'm from Iran, and we have saffron there. Saffron is a great antidepressant.

Lisa Yen

Delicious, too.

Dr. Mona Mojtahedzadeh

It's delicious, too! And I remember when I was a kid, I was like, I would hear this a lot... Yeah, make sure saffron is there. It makes you laugh; makes you smile a lot. So, lavender also has been proven with some antidepressant benefits…chamomile, none of this are to replace medication if someone is in need of, but not everyone will require medication.

And then there are factors for medication selection. So, if I want to choose a medication for a patient to complete the answer, the patient's prior experiences with other psychiatric medications, antidepressants, their responses, their tolerance to the other medications, what medical comorbidities do they have? What are the other drugs that they're using? So, what are the drug interactions I want to take into account? What way of administrating this medication am I looking into? Is that person able to swallow? Or would I want to do something that is more sublingual? And how long do I have? I mean, these SSRIs and antidepressants usually take weeks until they start working. So, you see what you want to take into account the patient's prognosis also. And some point in here, there's somatic symptoms, pain, insomnia, nausea, diarrhea, constipation, hot flashes, those are so important for me to be able to pick what medication would be best in which scenario?

Lisa Yen

Yeah, that's really helpful. And as you said, tailoring it all to the individual needs and preferences at the center. Yeah.

Dr. Mona Mojtahedzadeh

So yeah, centered and more customized. There are other interventional methods like TMS, one of our patients benefited so much she had refractory depression. She tried multiple medications didn't work for her. But TMS, or transcranial magnetic stimulation, was another modality that worked for that patient.

Lisa Yen

Sounds like there are lots of options. And there's a lot that goes into the thoughtfulness behind making that decision. And I like what you said, again, like the hand, hand to hand, collaborative approach with a psychologist or therapist.

Dr. Mona Mojtahedzadeh

A lot of our resources, you know, the good thing about this field that I am so blessed to be working in, is the fact that you can really collaborate with people. And we have individual therapists, group therapists, spiritual counselors, the oncology providers, everybody, you know, it is a really a teamwork.

Lisa Yen

Yeah, teamwork is important. So, the next question, if someone living with NET struggles with anxiety, how would you approach this patient? And how might you manage that?

Dr. Mona Mojtahedzadeh

So anxiety also, you know, understanding the cause of anxiety. You know, it's very common, as you mentioned at the beginning, when we were conversing around it that common for patients with cancer to suffer from just feelings of uncertainty, fear of what's coming up in future, fear of cancer recurrence continue to struggle with grief of the diagnosis. So, it's very common, but there are also other etiologies that can cause anxiety. It can be from their medical course, it can be oxygen is low, it can be the medications that are causing anxiety as a side effect.

So, you also want to look into the nature of the anxiety. Is it ongoing, is it like attacks, anxiety. So same as with depression, in general, understanding the etiology, taking into account patients' preferences, and overall non-pharmacological interventions for treating anxiety, do actually work a lot, if someone well informed on various methods, and recognizes what works best for them.

We have anticipatory anxiety when patients are going into their procedures, screenings, that you know, there are antianxiety medications that work rapidly, and they can even, oncologist do prescribe them to patients, and they can receive that prior to their upcoming event. But I try to also, along with the medications that are really helpful, great tools, very beneficial. Work with our patients, talk to them about other techniques that they can use and refer to our therapists, or a lot of them, they do already have one. And they're already benefiting from, if they need individual therapy. But talking about relaxation techniques, meditation, different techniques that work for the person are also very important here and giving them tools.

Lisa Yen

I hear this theme, it's not just like a drug that can be a quick fix Band-Aid to help with all those I mean, it might help with it…

Dr. Mona Mojtahedzadeh

…it might be, and especially our antianxiety medications are so, so helpful, like immediate release of the symptom and a lot of patients especially with attacks of anxiety, or anticipatory anxiety.

Lisa Yen

Yeah.

Dr. Mona Mojtahedzadeh

Will benefit hugely.

Lisa Yen

Yeah, so while medications can help, especially like "scanxiety," we talk about before scans, there's also lots of tools in the toolbox. And I love how you've talked about multiple approaches with relaxation techniques and psychologists and spiritual counselors and other people that can help along with it. So, you mentioned also somatic symptoms, so you know, sleep being one of them. And I know that's a common complaint for people, much less those with cancer. So, someone living with NET struggles with sleep issues, what might your thoughts be about how to approach that?

Dr. Mona Mojtahedzadeh

Sleep is important as you said. There are a variety of reasons that sleep can be impacted in someone with NET specifically biological impact from their cancer by virtue of you know, again, we talked about inflammation all that, but also can be potential side effects to whatever treatment, so we want to understand the etiology first, and also the nature of sleep issue.

Yeah, like what time of sleep? Is it more difficulty falling asleep? Do you wake up easily? Do you have just a long sleep, but you never feel like you had that deep sleep and you wake up feeling unrefreshed? Why are you waking up? If you're waking up is it you need to go to the bathroom? Is it pain that's waking you up? So overall sleep does strongly impact quality of life. Right? We all know that. And it can easily become chronic. And it also other than impacting quality of life, it can aggravate symptoms of depression, anxiety, pain, and a sense of well-being.

The NCCN survivorship guidelines recommend a good sleep assessment, even in survivorship. Anytime during your cancer illness trajectory, you need to receive good focus on sleep and to address that whenever needed. So as much as treatment, here also, you want it to be tailored and individualized. But also, this great CBT, or cognitive behavioral therapy, for insomnia has been proven to be most beneficial for chronic insomnia, meaning insomnia that is more than one month. And its therapeutic effects, compared to medication have been reported to last longer remain even at one-year follow-ups.

And I just want to briefly go into, we're talking about different parts here to this. And a lot of providers are familiar with it, they discuss it with their patients, or therapists, psychiatrists and we want to really introduce the idea of sleep hygiene to people. And I'm talking about this, I don't know how much of it I'm implying, but once you start running into problems, then is important right to start paying attention to all these hygiene recommendations. And I don't know if you want me to get into details, or how much time do we have?

Lisa Yen

Sure. And you can go ahead and share whatever you have for us.

Dr. Mona Mojtahedzadeh

So, there are multiple phases to this. The idea is to condition your brain that your bed is for sleep. And so, you know how this pattern of not sleeping, not sleeping, not sleeping, and then you just don't want to go to your bed and you feel like even panic. Not panic, but like you're really anxious when it's sleep time. I hear this from a lot of our clients, like I don't even like the sleep time because I have to sleep and I can't force myself to sleep.

So, you want to break this cycle. How do you do that? You want to actually restrict your amount of time that you're in bed. So instead of thinking that if I go early to bed and I wake up late, so I'm going to have a better sleep, compared to when I have fewer hours in bed. You actually want to restrict your sleep hours to only those hours that you're, you're really sleeping.

We recommend that if you're in bed more than 10 minutes and you're tossing and turning, you can't fall asleep, just get out of bed and go to some other, you know environment, that you do some relaxing activity and then once you feel sleepy again go back to your bedroom.

And then so [the] bed only be used for sleep or sex. All other activities reading including reading, TV, phone conversations, eating, drinking, computer work, has to be put to another room or environment, at least not on the bed.

And we're talking about also cognitive reconstructing, trying to change the negative thoughts that there is around sleep. When I'm in bed, I can't fall asleep, it's easy to start thinking about, "Oh my God, I'm going to look like a mess tomorrow... I'm never going to be able to fall asleep tonight." I mean this just is going to be continued to morning. So, you want to try to train your brain to think, “I mean, okay, it might take a while to fall asleep but it's still okay, I'll still be fine tomorrow. It's just one night.”

So, learning to let go and trust your body's natural ability to sleep. And then sleep hygiene. Yes, you want to go to bed around the same time every night, but pick that same time when it's, you're actually knowing that you're going to fall asleep based on your experience of the past prior two weeks, probably.

Refraining from eating like two-or-three hours before sleep. Avoiding alcohol, caffeine also two-or-three hours before sleep. Avoid bright TV, computer lights or phone screens one-to-two hours before sleep and try to be making your environment kind of quiet and dark as much as possible. People can practice relaxation techniques before sleep, whatever works, meditation, deep breathing. You just want to slow your breathing pattern and quiet your mind to get yourself ready for sleep.

And we do have medication, we have natural substances. I spoke of lavender and chamomile they're helpful also for sleep and reducing anxiety. And I never recommend antianxiety medications to be used regularly for sleep. They can be used when you have anxiety, but not for sleep. But you can speak to a psychiatrist, if you're in search of a medication, or you need one and the psychiatrist can pick a medication that works best.

Lisa Yen

So many helpful tips. And I know that this is audio only. So, people can't see me smiling and laughing because I think there are things that in that, that resonate. We all kind of go, "Woops, I'm doing that!" or, "Oh, I could do that better." And so that would help with our quality of sleep, which would affect our quality of life. Imagine how much better my days would be if I could sleep?

Dr. Mona Mojtahedzadeh

Exactly.

Lisa Yen

Now, as a caregiver myself, I have a personal interest in the caregiving experience. So, the next question is, what suggestions might you have for loved ones of someone living with cancer.

Dr. Mona Mojtahedzadeh

I have to learn this from you! I want you to share this first.

Lisa Yen

Well, what suggestions do you have for loved ones who are trying to support someone struggling?

Dr. Mona Mojtahedzadeh

Be like Lisa. I'm trying to be humorous here, I'm sorry. But really, it is true that you are being impacted too, right? I mean, not only by witnessing your loved one suffering, but also physically, I mean, all these aspects, you guys are sharing your journey.

So aside from that, making critical decisions for like family finances, things like medical decisions, sometimes you need to make those decisions too and the roles might change. Like, say the loved one who is now suffering from cancer was always your caretaker. So, the rules can change. So, all of this is huge change. And again, I don't want to take any credit on that. I've learned all of this from our wonderful patients and their caretakers, but really trust that as much as of the pain you also might experience, you can also benefit from help at various stages of your loved one's cancer journey, including even during their survivorship.

Lisa Yen

Oh, that's a really important thing that you just said, that it's okay also for caregivers to seek help. And to destigmatize that, that this is also hard for us as caregivers.

Dr. Mona Mojtahedzadeh

Yeah. And, uh, you know, it's really hard. But, like caregivers do not hear this a lot that you're suffering too. How are you doing? Go ask for help. Take time. I mean, because they don't allow people to tell them because they just put themselves aside automatically, to be able to be of the best care possible to their loved one.

But the caretaker will also benefit from validation, from therapeutic interventions, and everything that we talked to the cancer patients…like, work on your coping skills, what worked for you always, let's strengthen that. Let's recognize that. And yes, here it is. Doing something meaningful here. Doing something, say, journalism, joining support groups, sharing your experience, fundraising activities, just like when we talk to our own patients, like doing something that is meaningful to you. You feel that you're impacting even a greater population by doing that.

So yeah, just know that you also need to take care of yourself, make time for yourself, understand your own feelings, and then trying to find that balance between taking care of the loved one and managing your own life routines.

Lisa Yen

Wow, thank you for validating the caregiver experience. And just as we said that it takes courage for the patients to ask for help, it takes courage for caregivers as well.

Dr. Mona Mojtahedzadeh

Yeah. And at the end, just know that the caregivers are, they need to be telling themselves that I'm doing what I can. But there are things that are not under my control, it doesn't mean that I'm not doing

enough. So, trying to remove that guilt. That it's, it's not me, it's just the course and I'm doing what I can here and I can take care of what I can control.

Lisa Yen

Wow.

Dr. Mona Mojtahedzadeh

There are great resources through APOS The American Psychosocial Oncology Society, and the cancer support community for caregivers. Oh, and through LACNETS.

Lisa Yen

Thank you for that. Yeah, I mean, Dr. Mona, what you said was so powerful. Just that it's okay. You know, that you've done everything possible. And it's beyond our control. I mean that, I don't know if we hear that enough. I can say for myself as a caregiver, it's so hard during the journey, and we make it extra hard by taking that ownership on ourselves. So, thank you for just saying that.

Dr. Mona Mojtahedzadeh

You're welcome. Thank you for hearing it.

Lisa Yen

And, you know, I know you already touched on suggestions for coping with cancer and such, but I want to see what other suggestions you might have for coping with the cancer diagnosis. And I mean, it really does feel like a roller coaster ride or a labyrinth for many people. So how do you find stability and peace during all of the tumultuousness?

Dr. Mona Mojtahedzadeh

Lisa, I'm so excited to talk about this. Thank you so much for the opportunity. Really, it is yes again, we want to talk about recognize your feelings. Recognize is it grief that you're going through? Is it anxiety? Is it guilt? Is it guilt of thinking you're being a burden to the loved one? Is it guilt of blaming yourself for what happened? Do you feel guilty because of how you look at other people who don't have cancer? Do you feel guilty for that? And that bothers you like, you're like I wish I was there. So yes, the guilt is so important to really try to recognize and talk about.

Also, we tell our patients always try to remember your past stressors, challenges, right? Life has had other stressors, too. And what did you do during those times, even though this is like, not even comparable, but still what worked there, you can try to utilize here, or we can work together on strengthening it.

Okay, so I want to really talk about this book that Dr. Jimmie Holland wrote, which is called, Human Side of Cancer. And it is beautiful, in a sense that, in a lot of senses of course, but what the message I got out of it is really one of the messages was, that cancer, it takes away your sense of control. And that's really difficult.

And the caretaker, as we discussed can also, you know, struggle with that. So, this book is emphasizing, you know what, find your own comfort level with this term. And based on your own temperament, your

own coping styles, your belief system, and you know, this approach that you pick, everyone should respect that. Your providers, your family, your other support, they need to know this is your preferred approach. And they need to respect that there is no universal attitude that you need to pick. There are attitudes that work better than the other, but there is no universal like instruction in there.

And yes, some people are more optimistic, some are more pessimistic, but at the end, you see that both of those people can either struggle or heal. So, there are approaches to help better coping, right? There are. And as Viktor Frankl also shared in his book, I love these quotes, because you know, we all learn from them. “Our greatest freedom is the freedom to choose our attitude.” So, you can choose your attitude, but this is you who is choosing it, it doesn't have to be forced.

So, you are important, what you value is important. And you have the ability to choose what attitude you want to have, like, how do you want to cope with this. And the more you are clear as an individual on how much you want to know about your illness, about the treatment and all that, make sure you tell this to your provider, so that they do not give you too much information or too little information.

And again, cancer.org, or American Cancer Society, has a list of questions that helps individuals to prepare themselves before their, maybe their initial visits to the oncologist, to know what questions they should ask or they might have and make sure they don't miss those questions. So, it's a tool for them.

And then it's important to know that your personality traits affect how you behave but not how your cancer behaves. So, a lot of people blame themselves. So not everyone is a fighter, right? Or a constant optimist. And that shouldn't be something that it's another layer of stressor for patients that I'm not that person, then it's going to impact my cancer course. No, it's just following your doctor's recommendation. You be you. Value who you are, and everyone should value that too. And never suffer in silence. Ask for help.

As we discussed from the beginning, depending on your past experiences, overall emotional state, yes, so you can have different responses, emotional responses to your cancer journey. And it's important to ask for help when you need it. As I said, multiple ways of helping individual groups, peer support, techniques, relaxation techniques, and spiritual counseling for those patients who are seeking more spiritual counseling to face more existential crisis or questions.

And so yes, so juggling all of these challenges, living with a chronic illness, and still doing what you love. Right? You still want to do what you love; you're living and continue with treatments. All of this, it requires a great sense of hope and emotional resilience.

This is a quote from Dr. Jimmie Holland's book, that so we want to try to maintain that hope. And there's another book, When Breath Becomes Air, from Dr. Paul Kalanithi. That talks about even if I'm dying, even if I know I'm dying, I'm still, I'm actually living. I'm still living. So, there is hope.

And in another book by Viktor Frankl that says, "One who has a why to live, can bear with almost any how." So really, when you have a why, when you know what you're doing is meaningful to you. These are huge factors that help you maintain that sense of hope and emotional resilience. Getting through stages.

Lisa Yen

There are so many gems in all that you said there. So beautiful. I'm, I really appreciated all that. And you know one mic drop moment was when you quoted Viktor Frankl, "Our greatest freedom is the freedom to choose our attitude." And at the same time saying that the personality traits don't affect the cancer, and so we have the freedom. You can be you. So, thank you for that.

You know, hope is powerful. So, as you know, many of us deal with grief and loss, and not just meaning when someone passes, but the last question would be, you know, what suggestions do you have for dealing with grief and loss. There's so much of it with cancer.

Dr. Mona Mojtahedzadeh

So Lisa, you know, again, I'm just a small member here. And I learned this from you all in this field and a lot of patients and caregivers, but grief is just the emotional response to loss. And usually, what loss like losing a loved one, or a situation or desired state, a health status, right? Or a job or even, even if it was a desired or a planned change, intentional change, you still can go through grief.

And imagine how greatly difficult it can be if it was forced or obligatory and it was not in your plan. And it's we're talking about health, right? Taking away part of your health or death of a loved one. So as much as it is difficult, but we do not want to avoid it. It is real.

And you can't heal if you keep pretending you weren't hurt. So, it's important to understand there's no right or wrong way to grieve. And so just as many as individuals on earth we can have that many ways of grieving. So, people can really grieve differently based on so many factors, their personal characteristics, their coping styles, so it's so personal, and no one has the right to tell you, or me, how should we or should not we grieve. There is no normal way of grieving.

But, I mean, understanding it's stages, from Kubler Ross, that was stated in 1969. It is very helpful, because a lot of people go through those stages, and they might just skip one stage or go through the other. Some people still won't go through those stages, but we're talking about denial, anger, you know, finding someone to blame right? Bargaining. Why? Why this happened? How can I return it? Depression and acceptance.

Again, this framework should not be so organized, and it is not in people, even if they go through all these stages. Sometimes our responses are really messy, and full of ups and downs. So, Dr. Kessler, David Kessler brought a fifth stage to grief, which is called meaning. And you want to focus on meaning, and the love you carry within for what is lost. And then I read through your website, this beautiful quote, "Grief is the price we pay for love." I don't know who said it, but it's beautiful. This meaning finding can turn your grief experience into something more peaceful and more hopeful.

This is from Dr. Kessler, really trying to focus on how greatly we love what it is lost right now. And why did we love it so much? That's when you start finding your meaning out of it? What meaning can you bring from that love to the rest of your life? To the people, to other people? Do you find gratitude for the time you shared? Does it help you to realize life is so short? Do you want to change something or create a change in your life? What legacy do you want to remain behind? Do you want to create a foundation in your [or] in the person that the loved one's name? What do you want to do? Or what can you do to keep this from happening to others? You know how that would change your overall interactions with other people.

So this is where we talk about meaning and you know, even the nature of the relationship with the lost loved one is different now. But the love is still there. And it hasn't changed. And you can carry it within always, everywhere. And with cancer, when we're talking about cancer, we're talking about self-love. Why are you grieving? Because you love yourself, you love your body. You love who you are.

Lisa Yen

Wow. So powerful. I'm getting emotional. I mean, really, I love your permissiveness that it's okay to be messy and then just tying in how important it is to find meaning and how that's a way to share love. Not just of a loved one lost, but ourselves. And even the thing that's being lost, like our health, our job, whatever it is along the way that we're giving up whether...yeah…

Dr. Mona Mojtahedzadeh

Yeah, exactly.

Lisa Yen

And how that can really, tying in the meaning to love, is just a powerful way to look at it. So, I feel like I could keep talking to you forever and ever. But why don't we close with this, I mean, you just talked so much about how important it is to hold onto hope in all of this, what last words of hope would you leave with the audience?

Dr. Mona Mojtahedzadeh

So really, I want to go back to the messages that are stated in the book, Human Side of Cancer, there are like a couple of messages in the summary. Do not internalize remarks that you may have brought the cancer yourself, or that the mind body connection is so powerful, that you can think your way in or out of this cancer.

And then there was more than one way to deal with cancer, and doesn't have to be exclusively positive. It should be the way that works for you. So everyone needs to find their own way. And admitting who they are and also asking for help when they need. You know, I really want to also talk about because the like closing statement here, cancer patients struggle with multiple challenges at any given stage during their illness trajectory. But also, the struggle that I hear a lot like, I feel a burden to my loved one. I mean, she's not doing or he's not doing his usual life course because of me, and all that. And that's very, very normal and natural to feel that way.

So yet, as much as cancer illness is a really individualized, and isolating experience, but also, we humans, we are living together, and we love each other and we get impacted, just like when somebody's happy, we get impacted. We will just automatically laugh, and we will become more happy. So, the loved one, whatever they're doing, they're doing it for themselves, not for the patient. And they go through the journey too in their own way. And the pain, the joy, everything they go through it too. So, you're not alone. By real. Not that it is obligatory, by real, you're not alone.

You know Lisa, I told you I love poems. I do read a lot of poems too, that actually helped me to write poems. And there is a famous poem in Farsi from the 13th century from this, one of the greatest of all time, poets Saadi Shirazi, and I'm not sure if you heard this translation would be, "Human beings are members of a whole, in creation of one essence and soul. If one member is afflicted with pain, other members uneasy will remain. If you have no sympathy for human pain, the name of human you cannot retain."

And then the other thing I wanted to close with is cancer can be an identity challenge. So, here's the thing. Life is not always about doing, but being. So, who are you is not defined purely by what you do. But also, what you believe in, what you think of, and what you advocate for. What are some of the things you find most meaningful in life? So, this experience can really help you as an individual who is struggling with your cancer, your loved ones and your providers, to become better people to understand better their own values, their own mission in life? And, what are the legacies they want to leave behind?

Lisa Yen

Wow. Wow, Dr. Mona, I'm just coming away with so much. I know that all these podcasts are always educational, but this one especially is inspirational, and empowering. And I feel so blessed, personally too, for all your thoughtful words and practical tips, and just the hope that you're sharing.

Dr. Mona Mojtahedzadeh

Thank you, Lisa, so much for having me here. I am glad that this is an opportunity for me to also pay back. And it's helps me to feel I'm doing something, little. And thank you for your platform.

Lisa Yen

Well, you're doing something deeply meaningful, and we really appreciate all you do for the NET Cancer Community, both individually, to the patients and loved ones that you see and care for, and for all the work you do and research and as a whole speaking like this and sharing your heart with us.

Dr. Mona Mojtahedzadeh

Thank you. Thank you very much.

Lisa Yen

Thank you for being here.

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