NET Shared Decision Making
Optimising physician and patient consultations
Episode 2: Individualising Treatment Decisions

Brought to you by
Dr Mohid S Khan, Consultant in Gastroenterology & NETs, Clinical Lead, South Wales NET Service, University Hospital of Wales
Sally Jenkins, NET Patient and Patient Advocate

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Dr Mohid Khan
Welcome to our podcast, where we're going to talk about shared decision-making in neuroendocrine tumours, or NETs, how to individualise patient treatment and factors associated with that. I'm Dr Mohid Khan. I'm a Consultant Gastroenterologist and lead at the Neuroendocrine Tumour Service, South Wales, UK, and this is Sally.

Sally Jenkins
Hello, I'm Sally Jenkins. I'm a NET patient of 15 years standing. It's made a great difference to my life, but it's now stable and I live a very good life.

Dr Mohid Khan
So if we get onto the shared decision-making examples. Going back, you have the injection, the somatostatin analogue injections every month. And initially, you had to come to the hospital and there was no choice. But then after services developed, there is the home care service. So that injection can be delivered at home and a nurse comes out to inject, and in some cases, with some drugs, in some countries where the injection, or giving the injection, could be taught, so the patient learns how to give it themselves or a carer or relative could learn. And, I guess in the beginning, when you're having to come to the hospital, parking is always a major issue in UK hospitals, but a disadvantage of just having it at home is that you'd miss the social aspect, in seeing a nurse, seeing other patients. So it's important, I guess, that if we have home care services, that patient support, nurse helpline, ability for patients to have groups is really important.

Sally Jenkins
Yes. That's what happened to me. When I was coming into the hospital, there wasn't a nurse helpline and there wasn't a particularly extensive patient support group, so coming into the hospital was important because I could talk over the previous month with the CNS (Clinical Nurse Specialist), I also bumped into other patients. But then as the service was set up and things matured, then home care was better because there was a nurse helpline and also there was a well-established patient support group. So I was getting what I needed in that direction elsewhere, not from the hospital. That's when, you know, going home, being able to have it done at home, became much more advantageous. And I think it is for a lot of people actually. As long as you've got the other support, because it can be very isolating.

One thing about the nurses who delivered the injections is that they are very good at doing that type of injection, but they are not NET specialists and they don't really know what the injection does in detail. And so you can't actually discuss with them the sort of things that you can discuss with your NET CNS (Clinical Nurse Specialist) or other patients.

Dr Mohid Khan
And so it is important to have that ability to interact with the NET service, even if these injections are given at home or given around the country, if someone's travelling and, people travel around the country and Europe and, come back and so it gives that flexibility.

Sally Jenkins
Yes. Again, this is very individual. Because some people want to go off travelling. Others, different ages maybe, different stages in life, they want to stay home.

Dr Mohid Khan
And we see that. So some people, you know, do want some sort of routine and want to come to an institution or a practice in primary care with their GP. Obviously there are resource implications. But it is important to be, I think, giving choices to patients.

Sally Jenkins
Yes. We're coming back to shared decision-making here again. And again, that gives you a feeling of control as a patient because one thing that the cancer diagnosis does do, or any serious illness diagnosis does to a patient psychologically, is it kicks the bucket of certainty out from under your feet entirely. And I don't know if anybody's ever really got it back afterwards. And NETs are very uncertain.

Dr Mohid Khan
Yes. I think it's that uncertainty that we have to communicate. Similar to that, there's no right or wrong answer, right or wrong treatment. I think that there's a need to communicate that uncertainty.

Sally Jenkins
That's really important, because I've heard, and a lot of patients have said to me, ‘Oh, people say to me, oh, you can't be seriously ill because you've still got your hair and you don't have chemo, so, you know, you can't have serious cancer’. Actually, you do but it's just a different type of cancer. And so, because it's such a long-term condition, whereas as I said, you've got to reconstruct your new normality, then you need that feeling of some control and need some feeling of choice that you can steer your own ship. You can, you know, have your own destiny.

Dr Mohid Khan
That patient, going to the toilet and couldn’t travel, that reminds me of one of the very first patients I saw on moving. I remember her being in tears when I moved to South Wales because she had some bowel issues and just had to use public transport in a geographical area, which she couldn't drive and had to get to family and was worried about getting onto the bus and it was that uncertainty that I felt from her. But I guess the goals with the shared decision-making is trying to figure out where you can get to, and having some certainty of having that uncertainty if that makes sense, that living.

Sally Jenkins
Yes, I suppose it's a controlled uncertainty, if you know what I mean. There are some things that you can rely on and the rest of it, you just have to go with the flow. But the certainties, the things that you can rely on are psychologically very good for you, for the patient, it means that you can actually think, yes, I can cope with this. I can do it.

Dr Mohid Khan
And I guess, we have a cancer psychologist, so, they run courses on managing uncertainty or living with uncertainty as well, they put on the patient groups and patients, which, I guess it all boils down to having that shared decision-making process and then, coming back to it. But I guess we were talking about injections, so bringing it back to the injections. Obviously some injections, some people can be taught to self-inject and some can't. So there's a study, PREF-NET, that was looking at particular somatostatin analogue injections and comparing having an injection in hospital versus having it at home.

And there were some questionnaires to complete but also some qualitative interviews. So just freestyle interview and then some clever people who, not me, were analysing that data and out of the study there were quite stark results: 99% of patients preferred to have their injection at home. I mean, you can probably guess the sorts of things that they quoted and how it helped them. 'What advantages does having a home injection have?' I mean, we've talked about flexibility, is there anything else that you think would be an advantage of having an injection at home, have you had that experience?

Sally Jenkins
I think one of the advantages, again, it's psychological, in that you become less medicalised, if I can use that word. If you have to go into a hospital or even to a GP surgery every month, that says, 'Patient, a person who is ill'. If it's something that you can do at home, it's easier. You can carry on with your normal routine. You know, it only takes half an hour out of your day and it's not a problem. But it's also not pointing out that you are a cancer patient. Because again, that's the psychology of it. It's the way that people regard themselves and if you regard yourself as an ill person all the time and you're having all these reminders, and we have enough reminders of that, you know, okay, my bowels are not normal, I have to go to the loo more frequently than other people do. So I get those daily reminders. I don't need the additional one that, 'oh yes, next Wednesday I've got to take the morning out to make sure I go to the hospital'. That psychologically makes a lot of difference as well as the practical aspect.

Dr Mohid Khan
You're right. I think out of that study, one of the findings through the interviews was that it did give patients confidence, and quality of life was improved if they can have the injection at home, out of hospital. And, more psychologically, more comfort. With that study, the PREF-NET study, as well as the local psychological impact in a positive way, they're more confident in managing themselves.
So it's the practical stuff, the cost of going to a hospital and also the cost of taking time out. And if it's someone working then, you know, I know, sort of, my own story and my family's story, where you have to coordinate and who's going to look after, who's doing the pick-up, is work going to allow lots of appointments? And therefore… and if someone's self-employed, so self-employed people they don't have that sick-pay because they work for themselves. And that's something also which came out of that study. As well as the practical thing about getting to hospital.

Sally Jenkins
Yes, it can get expensive

Dr Mohid Khan
It can, and obviously there are concessions in various hospitals, in most hospitals, especially if you've got cancer. But just having that anxiety if they're driving, worrying about getting there on time and missing their injection and finding a parking space, was something that obviously came out.

Sally Jenkins
Yes. It's funny, a number of patients say, 'oh, when I have those injections, they make me tired'. I don't actually believe that. I rather think it's the stress of having to get there or whatever makes you tired. Whereas it's not a physical side effect. It's a psychological side effect. And some people say, 'oh, I get a dreadful ache in my leg'. Well, you can, but not necessarily and I think a lot of that is psychological rather than physical.

Dr Mohid Khan
Yes, and I think anxiety does make you tired and, you know, and everyone knows you tense up and you get stressed, and the mental activity and concentration, and then sort of having that adrenaline rush and then it goes and then you get that afterwards, the adrenaline sort of seeps out, and then you have that down and you feel tired. And you're right. It could be that, I don't know for sure.
The studies with the injections and neuroendocrine tumours such as PREF-NET, there's sort of systematic reviews of summaries of studies. David Cella's, where they looked at a number of different papers which also reported some of this preference for particular injections and the preference for self-injection. Obviously injections, if you get into technicalities, some of them are prefilled, so it's a syringe, it's ready-made. And some have to be made up and there's some solutions to make up, and then, you know, relying on a nurse to do it in the right way and they have to be reasonably experienced. So there's these other factors. But certainly some studies have looked at, the simple thing, the simple injections where it's all ready-made, there's more confidence generally in giving it.

Sally Jenkins
Well, again, we're coming back to control and confidence all the time aren't we?

Dr Mohid Khan
Yes, yes.

Sally Jenkins
And that's what good shared decision-making does.

Dr Mohid Khan
And I guess these are studies, similar studies and there's ongoing studies with patient-reported outcomes. In the real-world, PCORNET, looking at patient-reported outcome measures, responses to treatments and all sorts of settings. Patient-reported outcomes are essentially what you talked about towards the beginning of our conversation – questionnaires essentially. 'How do you feel on a scale of 1-5, 1- 4? Bowels, various symptoms and quality of life'. They're coming on board in real life in clinical practice. 'How do you feel about them in just real life, fitting them in?' and does it give you any information for yourself?

Sally Jenkins
It does actually. It makes you focus on how you are, which is good. It doesn't take very long now that we can do them online. It's quite easy. It becomes part of the routine, and I think it's useful because I do tend to look back when I get a little reminder to fill in my 'How are You' questionnaire. And I will look back over the previous few months and I think, 'Oh yes, I'm doing better than I was' or 'I had a dip then' it's quite useful to know yourself.
And when, sorry a slight sideline, when they were first introduced, I think, right at the very beginning, when you arrived, you were doing some data collection and you used it in a study, and I think it got as far as a poster at one of the conferences. Well we had a patient support group at that time. And when it came back that there was that poster and that was us, at one of those groups we had the poster and I said, 'Look, that's us. Somebody has taken notice of us, and this group'. It really

gave a boost to morale because we were all feeling a little bit ignored at the time. Because, as I said, we didn't have a dedicated service then, one has come now, but at that time, it was a really good psychological effect. So I think you get a group psychological effect as well as an individual one with that sort of thing. And then of course, if people aren't interested in statistics, well, then they don't have to look at them.

Dr Mohid Khan
I guess not. And on the individual level those questionnaires, patient outcome measures, it's helpful because it does allow the consultation to be tailored in a set when you can say, 'well, that thing there, that's important for the patient'. They've gone off the scale so let's explore that in detail.

Sally Jenkins
Is there also, like exception reporting? Don't some of the CNS's (Clinical Nurse Specialist) keep an eye on it? And if somebody is really dipping, they are well aware that somebody's having a bad time?

Dr Mohid Khan
On paper, it's obviously done in the waiting room, but digitally we've got systems now which are coming into real life, which in the real world which could help those shared decision-making processes. And I guess it's going back to those shared decision-making processes in the real world. I mean, how do these studies matter? Or do they inform what you think is important to patients?

Sally Jenkins
Well, yes, of course they matter. I mean, I have been a numbers person and quite often if somebody makes an assertion, I say, "Well, where's the research to back it up?" Because that is important. I mean, that tells you whether it's opinion or whether it is fact, as we see it, whether the numbers support it. I mean, there's always the interpretation, but if you haven't got the data, then you can't have interpretation. And I know that a lot of choices, particularly in the NHS, are made on research.

Dr Mohid Khan
And on evidence.

Sally Jenkins
Yes, on evidence, it's evidence based, you've got to have it. So I think some people understand the, you know, the necessity for it.

Dr Mohid Khan
Yes. And I think that's important because some of these studies didn't exist five, six, seven years ago. And clearly these have shown now that there are a number of factors in patients' experience that, as well as patient outcomes, are important in this decision-making process when it comes to these treatments.

Dr Mohid Khan
Thanks, Sally. An interesting conversation. So as we come to the end of this podcast, I'd like to leave the audience with some concluding points. So what do you think the takeaways of our conversation have been?

Sally Jenkins
From the patient's point of view, what patients want and need, I feel, is to feel that they are being listened to carefully and their views are being taken into account because what that does is give back a feeling of control, that something like a cancer diagnosis takes away.

Dr Mohid Khan
And from the clinician perspective, there's communication skills, empathy, the ability to tailor the consultation and information and tailoring shared decision-making to the situation in the patient because people are different. When it comes to the injections and the choice in certain areas over injections. Taking into consideration those other factors we talked about in terms of listening to the patients and how that would impact them in terms of the side effects or how it affects their life in terms of flexibility, travel, etc.

And so I think we've covered quite a lot today. So thank you. Thank you very much, Sally. So, hopefully we'll see you soon!

Tonke de Jong
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