Okay. So should I just start or do you want to fire up my slides?
Right. Okay. So I'm going to try and tip this so that people can actually see my face.
All right. Okay. So first of all, thank you to Vanita for inviting me to this talk and
thinking about psychosocial oncology in the geriatric space.
I want to quickly introduce the psychosocial geriatric oncology research team so far.
So we have Kumar Profaashen Vanita from Tata and we have Shwata from IIT Bombay, who is also a psychoncology professional.
And from IIT Hyderabad, there's Shraddha, Shubhirman, myself, from IIT Hyderabad.
And we're obviously looking to grow and this is just a team that's grown over what the last three months or so.
So yeah, we intend to grow far far far more than that.
So I know that many individuals within this room already are probably aware of the burden
or the prevalence of oncocare within the specific population of the elderly.
But what is very interesting is that almost all the people who belong to the older group exhibit issues related to say weakness
or nutrition, functionality or mental health.
So when the way I'm going to design or talk today is going to be more like a story to kind of let you know how we came about
and how we put this entire concept of the unmet needs together in geriatric oncome.
So when Manita reached out to me, this is what I first did, right?
I went to the drawing board and I said, let's see what's all the research out there.
And this is the first thing that kind of came glaring at me, that practically all the patients who belong to this group
were exhibiting these comovertities or issues.
So then we obviously looked at the psychological impact of having geriatric oncome related issues.
And again, you can see that so many aspects are impacted when it comes to having cancer when you're older.
So psychological, social, barriers, quality of life, everything takes a hit.
But what was very interesting was the irregularity of available clinical staff really stood out.
This was opposed to children who had cancer and also adults who had cancer.
Specifically the geriatric group was struggling with the fact that they had irregular clinical staff available to them.
That means basically that they were not able to cope when the nurse that they were used to seeing was not available to them that day.
And similarly a technician or even doctor. So they were not comfortable with this.
So what does this mean, right?
So these are what popularly a lot of us know to be called piarose or prongs, patient reported outcomes.
So these are the outcomes of what patients were experiencing at the hospital care or at the health facility that they were at.
So basically what I mean by this is that these are outcomes of having been plugged into the system.
But the question really is how are they even experiencing the system, right?
Because it's a system that is then leading to these specific outcomes among these individuals.
So as I started doing the research, I mean we also do a lot of prem work in other domains, but I was very interested to understand it from the geriatric space.
And so we were really trying to unpack patient reported experience measures of pre-s as well they're called patient reported experiences.
Now this is slightly different to pros because what we're doing over here is we're trying to understand how the care process was impacted
and what are the areas of improvement for that specific health care system, all

right?
So prongs usually help us measure what is happening when a person is part of a health care system.
Where exactly why are we saying that the person is depressed?
That's an outcome of having experienced cancer, right?
So what is that experience?
And it covers two main domains.
One is called relational.
So what we're doing over here is we're trying to understand relationships.
Did they feel like the doctor for example was fulfilling their wishes?
Did they feel like the nurse was maintaining eye contact with them?
Did they feel connected to the health care system?
These are the kind of questions that we're asking in the relational domain.
And in the functional domain we're asking very practical and logistical aspects of the care system.
So are the facilities that are available, sorry what happened just now?
Okay, are they really available as management what might think they are?
So you'll see in this image over here that a prem measures or looks at a variety of domains.
So we're looking at something like effective treatment from the trusted professional all the way through to are we getting enough emotional support, empathy, respect?
Are we getting a very clear understanding of the information?
Are we getting support from the health care team in terms of doing better with my own self care?
Is my family and friends, are they like genuinely being involved in the care continuum?
So there are a whole lot of questions that you know patient reported experiences can measure for.
And one such measure and here I'm going to linger for a bit because it's a busy slide is called the Supportive Care Needs Concept or Model.
And you'll see on the image over here it covers a lot of domains.
It practically covers all the domains that we were talking about in the previous slide.
And what Supportive Care Needs looks for is how is the individual experiencing health care delivery in the domains of psychological wellness, physical, emotional, practical, informational, spiritual and social.
So it's really covering the entire 360 degree arc of what it's like for an individual to be a part of your hospital.
So Supportive Care Needs are very, very important.
And I'll get to why they're very important in some time.
So I went with this model to Venita and I said listen, I feel like let's start over here.
Let's first of all understand how are people experiencing the care that you are providing in your care facility itself.
Let me understand and observe and generate evidence for that specific health care facility.
The reason why we decided to do that and then transfer it to other health care facilities.
So if anybody in this group is interested, please contact us.
Is to really understand across India what are the similarities that we can map for patients, but also what are unique to specific health care facilities.
So we've done a similar study for different hospital models within Hyderabad.
And we realize that you'd think that a charity hospital will do really well in terms of experience outcomes.
That's what you'd think.
But actually did very badly compared to a corporate hospital and compared to the RCC.
In fact, actually the RCC did very, very well.

It was exemplary above the other hospital setup.
And you'd think again, how is it that an RCC experientially patients are experiencing the RCC far better
than they are a charity based hospital?
And both of them have free care services.
So that's why I said to Vanita, let's look at this from a multi centric perspective.
But also let's just look at what care facilities are being provided.
Because I would hate for us to walk out of yours thinking that, oh, you know what, patients are very depressed when they're geriatric or patients are feeling socially alienated.
Why?
Why are they feeling this way?
You know, what can we do?
And their point of contact in terms of, you know, they're reducing that feeling of social isolation.
So then of course, you know, we had to kind of identify our measures.
And at this point, I would like to kind of say that, you know, I do both qualitative and quantitative work.
My training isn't quantitative, but my love is for the qualitative.
So I managed to marry both of them.
And so we first looked at what other measures that are available.
And these are just the four that I'm mentioning over here.
There's far more, actually.
Measures available specifically towards understanding supportive care needs.
So Rob Sanson Fisher out in Australia was the one who first identified this conceptual framework and then, you know, designed the questionnaire accordingly.
So the previous study that I referred to on adult cancer patients used that particular SCNS, you know, questionnaire.
And we are using the cane, obviously, because we're looking at patients who are older.
But there are basically what I want to impress upon you is that there are a whole lot of questionnaires out there.
If you want to genuinely ask yourself, is my hospital doing what it says it's doing from the point of view of your main customer, your patient?
Right? So this is what it looks at.
There are also now supportive care need measures that look at it from the caregivers' perspective.
These are mainly emerging multicultural settings and settings like ours, where caregivers are also major decision makers.
So what does it mean when we say a supportive care need is met, unmet, and undement?
Okay?
So a met supportive care need is basically one where a patient is saying that all that I want is available to me.
So it indicates that there's a high chance that you have achieved what you wanted to achieve in this space for this patient.
An unmet need, then, is a gap, an opportunity for a healthcare facility to provide better services, because currently they're either absent or they don't know it's available even.
And then, of course, there is this beautiful space called the undermet need.
Now, undermet needs are something that actually have emerged mainly in India.
So myself and another group have done some work in this, but in the pediatric space.
And what we've discovered is there are these needs that are kind of met, but not really met.
And that means that they have fallen short of quality accessibility or even alignment to the specific need of that patient.
Now, one such undermet need is often medical information.

So a doctor will say, I told this patient side effects the home gay, you know, after this particular treatment.
But the patient is surprised. They're like, how did I get this side effect? I didn't expect hair fall.
Right? But, you know, it's a common knowledge and the doctor assumes that you know it.
And they assume that the healthcare team has already advised and informed the patient or the caregiver about a specific side effect.
However, the patient did not know about it. So this becomes an undermet need because it was informed, but not quiet.
So it is still considered an unmet. But for us, it's important because we know that the facility, that opportunity or that service is available.
It's just that it was not adequately available to the individual.
So what happens when need needs go unmet? And this is where really we wanted to kind of understand and highlight to management as well as individuals who are interested in the space that an unaddressed need.
So a need that is there and it is not being met, leads to treatment abandonment, non-adherence and discontinuation to follow-ups.
This is a really, really big problem. And we've now seen through global literature that it really does funnel down to that.
You know, a lot of abandonment, a lot of loss to follow-up is really happening because patients are not experiencing that particular hospital or clinical setting, the way that one has imagined it should.
So then coming to the global research, what's available to us, we know that the most common unmet needs are psychological, emotional, informational, medical, physical and daily living.
What's interesting, and you'll see over here, even in global stats, spiritual needs are being met by hospital facilities.
So that's very, very important for us to establish and know.
Now, unmet needs were also highest at the time of diagnosis and at the time of receiving treatment.
So this is something that all of us need to be alert to, that people will have, you know, not, if you know already, right?
Like when somebody is diagnosed with cancer or when they're about to start a new treatment, they will exhibit high levels of anxiety.
Why? It correlates with the fact that their needs are going unmet at that point.
It could be an emotional need and not necessarily an informational need.
So it's important for us to really appreciate the fact that unmet needs seem to be most expressed at this time point.
And unmet needs are linked to frailty and also the patient report an outcome of poor quality of life.
Now, how are unmet needs predicted so far by socioeconomic and medical factors?
Like gender, you know, existing, preexisting, depression or so of comorbidity in that space.
Being unmarried, income, head literacy and also receiving multiple treatments are having greater symptom burdens.
Okay? So, but this is global research.
So we then zeroed in on, and this is my last slide, I promise you.
When we zeroed in on what is available to us in terms of research in psychosocial oncology in geriatric space in India,
we came across about eight studies and of which three of them didn't have the kind of research rigor that I could report it.
And so these are the studies that I'm able to kind of report at this point.
And what they found was, of course, you can see a lot of, you know, pros out over here, right?
Like there's poor health, HRQL, there's a lot of pain, lack of awareness of any specialized support, anxiety, depression,
poor social support and financial constraints.
But what we saw was there was no qualitative piece at all, and there was only

quantitative work,
and all of it looked at patient reported outcomes.
Nothing looked at how the care system or provision was being experienced by the patient.
Okay? So this became very, very pivotal and important for us to appreciate and understand.
So we were like, okay, so there's no research in unmet supportive care needs.
What do we do? Of course, we do the research.
So what we then realized was, listen, the work is already indicating naturally towards studying or understanding unmet supportive care needs.
One, it's already showing us or it's indicating to us what are the deficits in the care delivery.
So it's not telling us what these are, how these are, why they have come about to be.
None of those questions are being answered, but we do know that there is a deficit in the care delivery,
which is why they're being expressed in such specific ways, like pain and lack of awareness and so on.
And it also shows us or points us towards what are possibly the concerns that patients might have.
It could be about longevity, it could be about social isolation.
We don't know, but it does definitely point us in that direction.
So what are we doing now? And what can we do in terms of collaboration?
I'm putting this out there in the hope that more organizations want to align with us
and really map unmet supportive care needs in their care facilities, especially with the geriatric space,
is first we want to document what are the supportive care needs, what are needs, first of all.
Maybe spiritual needs are not needs. That patients are even feeling because they're getting it elsewhere anyway
and they're not linking it to the particular hospital. Maybe that's why it didn't come up at all.
So we want to look into what are the types of needs, which are being met, under met or unmet,
the predictors, and at what point do they seem to be the most needed, what's the impact and all of that.
So really, really map what are the supportive care needs are.
And eventually provide some kind of clinical direction in terms of care service provision.
And finally, hopefully, we all end up at this MEKCA called guidelines and protocols.
So eventually we want to sort of direct a lot of this evidence towards how can we improve the care that is being provided to those who are older.
So I'll stop over here and thank you very much for listening to me.
And yeah.
Mm.
Right, so should I wait over here or should I go and then question and answers us later?
Okay. Although I think it's very early in the morning and I've wowed everybody.
Yeah, I know, I don't need that.
So have you, what is your, I mean, in the literature that you have, what is the compliance to treatment?
What is the rate of compliance to treatment?
There's no research from the psychosocial perspective.
There's no research that has looked into adherence to treatment.
What some of the research has indicated is that there could be anywhere between 50 to 75% of abandonment of treatment.
So halfway through dropping out.

So I mean, there are many, I mean, either it is the patients are not aware and even the caregivers, even there are hurdles in their mind that the patient will not tolerate treatment.
That's why the caregiver, it becomes difficult for the caregiver to get the patient for treatment.
So in our study also we had encountered about 25% abandonment of treatment.
So, but I think rather than the physical barriers, I think a lot of things need to be done mentally.
They should understand that not all elderly patients are same and many patients can take treatment.
Yes, exactly. I think also that, you know, a lot of it is lost to like what I was, you know, detailing over here, right?
So much is lost to in terms of their emotional needs in psychological and also, you know, there's a fear of losing your daily function, right?
So these are the things that I feel the healthcare team should really respond to and ask questions around that.
Any questions from the delegate?
Another measure is to make more resources on my needs in our second.
Yes. Okay. So that's exactly what the reason why we're generating the evidence.
I cannot come up with suggestions at this point because we don't know what are the unmet needs yet, right?
And I'm very cautious about being able to give any kind of suggestions without looking at the research, I'm sorry, but yeah.
But I'm sure there will be unmet needs, right? Like, existing research at least indicates towards emotional, psychological, daily functioning and information.
So at least existing research in non-geiatric spaces is indicating towards this in our, you know, patient population.
Is the feedback system works here?
What do you mean by a feedback system?
Asking the feedback, how is the treatment gone? How is the service gone?
Yeah. So usually that does help because it kind of restores or keeps intact dignity in care.
So asking individuals, how are you doing? Are you okay with this? Is the satisfactory for you?
Does help restore that sense of dignity and individual care?
But I've, in my experience at least I can tell you, you know, as a consultant advisor for many hospitals,
that it usually also helps if to have an external agent every now and then come and do that lipstick measure to see whether people are really responding because they want to be appearing compliant to, you know, literally compliant because, you know, you don't use the word compliant that much any longer.
But, you know, they say it to please the, you know, the healthcare provider.
So yeah, so usually it helps to have an external agent to come and just check that.
Yeah. Thank you.
I think this current generation is somewhat in between. Sorry.
In between the earlier family, you know, pattern of a big, big, big, big, big, combined, you know, joint family.
Yeah.
And not the art patients now, a lot of their children at least the more micro-fatiens their kids have gone with the USO.
And they are not used to actually living alone and taking care of their needs.
So they're selling a couple of days ago.
We had this patient with lung cancer who was just, this is elderly man and woman living.
And they were really close to the hospital.
When he was terrified, it's just the poor girls, my kids are not, I don't know if it's the case.
I don't know if it's the case.
But I don't know if it's the case.

So they are, you know, they are, it's not, not the macro-factor.
Yeah.
So they are joint families and they don't know how to do.
Do you have any recommendations or suggestions?
Also, I guess as it goes onward, we have a way to deal with this.
Yeah.
And the system living and things like that.
But this is a sandwich generation, I guess.
So it really does help to identify.
NGOs, for example, like good fellows who can be, you can come up with champions and people that you can train,
who can become the liaison between the elderly parents over here afflicted with cancer and the kid who's not around.
So they can be the ones who kind of provide that information and feedback loop.
A lot of the terrifying feeling is coming because they don't know what they're up for, getting into.
And they don't know whether there are enough people to support them, right?
It's a lack of confidence, essentially.
So aligning with NGOs who are willing to kind of work with older people and, you know, the issue though is that they need to also be specialized in this because it's so specific.
It's not like diabetes, right?
So yeah, that could be a good solution to the issue.
The other thing is, you know, I'm sure that this is the AI generation.
So, you know, coming up with an app that is also very specific to this where the EMR is a little bit more detailed and is recorded
and allows for the passive, you know, pressure that they might experience from their own kids, as well as, you know, the kind of support that is another opportunity for us.
But I also feel that community health intervention is going to be the way we have to go with this, right?
The other extreme are the uneducated patients actually.
This week, completely, the opening I saw the patient was, I mean, not being taken care of by the sons.
They are living with their families. They don't know. They will come and look at us.
They don't have a smartphone also. I mean, how do you think we can do?
No, I agree with you. That is a very big issue because a lot of them actually just get abandoned at the hospital.
And she was doing a home. I mean, how does it work? And because she's now something so uneducated.
Completely amputated. Yes. I mean, that is really an issue in terms of the ones who are belonging to the lower economic strata.
Yes.
It's of age-related, the relative functions that themselves want to depend on their care, specifically children.
I mean, when we deal with the geriatric patient, so they themselves don't want to take initiative.
When we ask about whether they want to know about their treatment or diagnosis, this is the don't they are doing.
So in our culture, still they don't have, we can say, I mean, in a mind or in a culture, basically culture, they don't want to ask.
So we need to psychogicate caregivers, actually, to speak to their patients, elderly patient, what exactly they want.
Even though they don't take initiative, I mean, patient don't take initiative, but we need to speak and that counsel and that support, specifically support that it don't happen in half.
And we can, I mean, to get the speak to the patient and caregivers.
So it will help to know and they can express well.

To sensitize caregivers, essentially, right?
Yeah.
So we need to actually care give a, we need to have a good care give a support to take initiative so that patient will, I mean, they will know what will happen entire the treatment, what is their role.
And then what is their importance also?
They are put, I mean, they are important.
In our country, then it is not happening, but that as a healthcare professional, as a psychologist or a psychologist, that we should do something. This is that one step.
Yes.
Yeah.
And listing formally and listing caregivers, right, as part of the healthcare team.
Yes.
Yeah.
Yes.
Yes.
Yes.
Yes.
Yes.
I just had a question. In terms of, you're talking about we need more research.
As a researcher yourself, what barriers have you faced to, you know, because in India, research in, you know, psychological health is anyway, there's a lot of dots.
We don't have standardized scales for, you know, the general population forget, you know, populations who are currently in oncological care.
So can you tell us about your experience of, you know, barriers you have faced as research and what do you suggest, you know, have you, do you have any suggestions for how we can go around?
Great. Thank you. No one has asked me this question in my 12 years of working in India so far. Thank you.
One is a very big barrier that I encounter is not having enough people who are interested in psychoncology research.
And then comes the added caveat, not enough skilled people.
So I spend a lot of my time actually skilling people on how to look, think, research, do research, write research.
So that is a very, very big barrier, the lack of, you know, capacity.
The other thing is that there's a lack of interest. A lot of the research that I do in psychoncology and I've been doing it for, believe it or not, 20 years, is all because I wanted to do it.
I very rarely come across, you know, a gift like Vanita, which was an interest and actively supports and really puts that there weight behind it.
So it's been a bit of a solo, you know, ride. But I mean, things have changed. I mean, there are far more psychoncologists out there now who are showing an interest.
More people who are touched by oncology and so they're showing an interest. And there are some doctors who are seeing how important it is to include this as part of their work.
Another area that I see in terms of research that is very problematic is that people don't understand science properly, you know.
You know, they will not understand that unless you design and put, you can't just talk without the evidence.
I am very, very scared about things like that. So I think really understanding science research and what it means is another barrier.
So I do a lot of education around water science also.
I just want to also respond to that. This is something very close to my heart.
Maybe this is not the right program. Two or three things.
One is advocacy is very important. So I think in India, so in India, here, I don't have to think.

So he's doing a lot of work on patient advocacy. So if the patients say that this is something that is important and that's incumbent on us to make the patients understand that any treatment,
that we do in the clinic has come from research.
It's not that somebody dreamed it up in their head. The only way to know something works is through research.
So one is advocacy. The second thing, again, this is not that I have put on but incentivizing research.
I do not show how it works at all. At least at all institution, research is not.
That incentivizes me to do it.
And you do it out of your time, out of your interest, you do it at home, you do it after that.
I think if it's a thing in China, it's been incentivized.
You can see the research output from China. It's all good to do.
So in most couple of things, all of us are researchers and clinicians and scientists need to spread the word.
We don't have that common mass of people, that the minimum common mass of people will force the people to know.
But I also agree that it's one is incentivization, but I also feel like management itself does not give you that time.
They don't give you one research day. It's so shocking. That's not the case in the West.
I know that it's because the doctors are overloaded.
It's the other way. The load is also higher than research.
Yeah.
In fact, basically people are doing more research.
That's true.
Any more questions or can we wrap it up?
Yeah.
All right. Thank you.