For the next talk, I would like to invite Mr. Sujair Bandari, who would be enlightening us on the psychosocial support for older patients with cancer needs and solutions.

Yes, hi everyone.

So, when I heard in the morning that we already going to be talking about unmet needs, I was wondering what am I going to talk about, you know, finally, when my turn comes.

And it seems like there is already a lot of awareness in terms of what there are unmet needs.

There are, you know, needs of geriatric patients which are not met.

It's important, however, for us to also locate our discussion in a context that discussion is happening every year, discussion is happening every day, we all talk with each other.

But still there is a gap, right?

There is still a gap over here of the needs which are unmet.

And we think of social needs as something that we can delegate, you know, to para professionals, to allied professionals.

But I think it is important that even the medical professionals realize that they are part of the social need of the cancer patients.

It is important that when we talk about geriatric population, there are intersections of, you know, being part of an older adult population and then also being a part of individuals who have been diagnosed with cancer.

And there is a lot of overlap in terms of the experiences they have which is compounded by, you know, the ailment that they experience.

Already as individuals who are, you know, in their old, later adulthood, they experience neglect, social withdrawal, they experience routine changes, you know, because they are older, they experience some sort of existential, you know, fear is also.

There is some sort of guilt and shame that they are being burdened to people in their family.

And of course they have to also deal with the physical and mental decline that they experience due to, again, as the age.

And these are things that of course are further compounded when there is diagnosis of some sort of terminal illness, right?

And it is important that we not just think about it as intersection of just age and being a patient of a terminal illness, but also there are questions of class, questions of caste, right?

That comes in a question of religion, okay, because you know, social, social, you know, aspects.

We cannot ignore these things because the way we express our social needs are not going to be uniform, right?

Even something as simple as anxiety, right?

When a person comes to you to talk about anxiety, they are all going to say, kimooji anxiety over it.

Especially older individuals who may not have that language to communicate their needs to you, they are going to say anxiety over it.

They may say something like, you know, kushto dillme dhadhir sawarayamun shay.

They may say, you know, peid dukta mama shab, which I bought dar-dulag raha, right?

The language that we speak don't necessarily have, you know, ankles in the language in which we learn our skills as professionals, right?

So it is important then that when we talk about social needs, we acknowledge that there is a doth in skills also, all right, from the side of professionals, all right?

That needs to be addressed before we get into the social needs in the lives of the patients.

Now, if we are to think of social needs, I can think of it in, you know, four dimensions, instrumental needs, do they have financial assistance, you know, do they have assistance to carry out their activities of dilliving?

Do they have tangible means of obtaining the resources they need in order to, you

know, have effective treatment?
We spoke about so many gadgets, we spoke about so many solutions over here, but what is the accessibility to these things, right?
How many of you over here work in rural areas by show of hands?
Anyone? No one? Not now, but again, we have shifted to cities because there are better opportunities, better infrastructure to work with, perhaps, and rural areas, there isn't, you know, infrastructure available for people.
Often, you know, I, one of my students also has now started working at Tata Memorial in terms of what is the experience of, you know, the kind of people who come in, you know, what is the experience of the social support that people need.
And they say, especially when people come from rural areas, there is a sense of abandonment because they are basically leaving everything they have behind and coming to the city in order to, you know,
seek treatment over here. And this is basically there one shot at, you know, some sort of chance at survival. And this is in case of, you know, when the space is not going to palliative, you know, it's more curative section, right?
Palliative where there is loss of hope, right?
Ka kernikabi, right?
We have appraisal based support, like do the patients have means to evaluate their own actions, right?
Do we tell patients how to gauge whether the treatment they've been prescribed, whether, you know, whatever it is that we tell them to do as a part of the care, to know whether it's working or not, when to report, you know, things to the doctor, okay?
When to sometimes just, you know, it may take time and be patient, right?
Do they have means to seek self-affirmation, right? Are there ways in which we have asked the people, asked our patients, you know, to kind of,
kutko dilhasa de nakele, right? Have we provided some means, some ways of doing that?
In terms of information support, do they have someone to answer their questions?
Because one of the biggest things when this diagnosis is, what does this mean for me now, right?
How many of you can, you know, if I ask you right now for recommendation of some sort of resources to give to someone who does not speak English, okay, who speaks in Hindi, how many if you can recommend me resources to, which will be comprehensive enough for an older geriatric patient to refer to and know what is set, what are the possibilities for them?
Are there resources? No, they aren't. Do they know how to solve the problems that may encounter, right?
To understand what to classify the problem. And that's what I just also spoke about in terms of we don't have the language, right?
To classify the kind of problem we are facing. There of course can become confusing even for the, you know, tacticianer to understand what is it they're talking about, because again, the language in which we learn and the language in which people speak, there's a gap, right?
Who can guide them in decision making? Now this is where, you know, again my question is, do we see ourselves as part of the support system, as social support system,
or are we just as practitioners thinking, me like our medical professional, I will do the treatment, medication part,
and Baki Ka will be handled by the social worker and psychoncologist, right? But for the patient, you are, they are not exactly the ones who are prescribing medications, right?
And as much as training, an experienced psychoncologist would have received, it is eventually the medical professionals who will have a better idea about side effects, a better idea about what patients can expect in certain kind of treatments, and what are the alternatives.
The first point of contact, right? After social worker, for the treatment part, he is a medical professional, right?

So how much training do medical professionals get? How much importance is given to communication?

Because science communication has now become a very, you know, budding field where being able to speak in a, you know, relay information in a manner that is universally understandable, and among professionals we can communicate.

We are having these meetings great, but this is a very small, small section of, you know, the medical professionals that is, that is, they are here today who care enough to turn up at today's meeting, or maybe even discussed amongst each other.

Most of them are struggling to maybe even keep up with the patient volume or even keep up with, you know, the kind of treatments that they are prescribing, working, not working, all these things.

And then emotional support, right? Do the patients feel loved, right? Because patients have lives before they came to the hospital.

They have lived full life, especially geriatric patients. They have seen so much.

They may have undergone abuse. They may have undergone discrimination.

They may have undergone economic hardships. They have had a life cancer, care, disease, and difficulties in the Annavala.

They may have, they have already come with the complexity of emotional difficulties, of relational difficulties, right?

So do they have people in their lives who care, right? We ask Kaun and Karpa, Sambal Nagavi, we try to find out Karpa Kaun and but the question is, are they people who they feel comfortable with their life?

Or do they feel comfortable with? Or do they feel that, okay, in the eventually, I'm a birded goose person, but now they're my relatives, so I have to rely on them or co-option in my repass, right?

Do they have people who they can trust? Because often being in a state of terminal illness can put you in states where you may have entered a point in life which you would have never foreseen for yourself, of embarrassment, being in a state of weakness, of dependence, which you would have never imagined.

You would have imagined certain things of course that would have come with old age, but the kind of dependency that comes with terminal illness is a very different thing altogether, right?

So these are the kind of supports that we need to talk about, alright? Again, there is awareness, but the question is, what are we doing with this awareness?

So psychosocial support is something that is relevant to treatment outcomes because it is not just a matter of whether a person is going to take the medications or not, because there are so many other factors which come into picture in terms of treatment,

adherence, right? The motivation factors, there are social factors, affordability of medications, there are AIDS, yes, for trying to buy medications, but from what I understand, it does not cover everything.

So what is their experience then to gather the finances to be able to get the support that they need, right?

So these things come under the psychosocial support, the experience of being able to seek help, seek finances, seek support is what we are talking about when we talk about psychosocial support.

So it is the availability of opportunities and structures, okay?

Which can fulfill needs that arise in individuals' mind and environment, okay?

And there can be anything related to their self-image, roles in the family, experience of health rate events, all these kinds of things come under psychosocial support.

And when we talk about psychosocial support for people who have been diagnosed with cancer, there is an additional question of, okay, now I don't have asthma or an ulcerative,

now I don't have as much time as I thought I would have had to, you know, sort things out.

There is an additional stigma also, there is an additional label also that I am sick now, and I am going to be seen as a sick person, right?

And how does it affect,

that's right now?
Laptop is round of battery I think.
Maybe we can take few questions for this part of the talk.
Sure.
Thank you.
So, social support question has part of the GRIAT assessment, which is from the US, and that is asked, do you have somebody to talk to?
Do you have somebody to take you to the hospital?
Do you have somebody to cook your meals?
And all patients have that here.
So those are absolutely not the right questions.
So when we found in our GRIAT assessment, the social support domain, nobody was vulnerable because everybody had all of this, but our patients had other things.
My association with Sujai is how do we ask the right questions and develop a social support questionnaire for our GRIATric oncology patients, that is a relevant questionnaire.
So this has led to the genesis, so that's where it is going, so if you want you can ask that.
No, it's okay if you have a question, all right, okay.
So as I said, there are things which are going well in terms of there is awareness definitely, there's availability of government to a certain extent.
There's certainly more, there's an increase in availability of psychoanchologists and professionals in other allied fields.
There is a shift to a more collaborative approach where now all professionals are working together in order to provide care for their patients.
But the question is, what would be done better, right?
There needs to be training of for communication, not just for psychoanchologists and social workers, but also for medical professionals, okay.
There also needs to be some sort of standardization of care, right?
Because there is so much subjectivity that comes in over here, but eventually for goal is to move towards, you know, providing some sort of universal standard for social support.
Then there should be communication, there needs to be some sort of, you know, common criteria that needs to be established, but of course, culture specific criteria also needs to be taken into consideration when we are talking about regional differences, right?
Increase in availability of caregiver training facilities in tier one, tier two cities and rural areas.
There are almost none when it comes to, you know, caregiving facilities, carelet training.
There are facilities which, you know, for people to admit patients in, but what about caregivers would want to learn how to take care of the loved ones who are, you know, terminally ill.
And especially if it is someone who is an older patient, it's likely that they have kids who are working, who may not have the time to be at home the whole day, especially if it is someone who cannot hire additional help, they don't have the finances for it.
So what is it that they need to know in order to ensure that, you know, the person at home, while they're gone for work, you know, what can be done to take care of them, right?
There needs to be centers which provide information, you know, for oncological care because again, there is, you can't have to just go to doctor in the first school because sometimes people, as I said, as someone said just today, Google, Google, Google, Google, Google, you know, misinformation is very easy to spread.
But if there is a credible source of information that is available to everyone, not just people who are English speaking, people who have a good handle over Hindi, Marathi, whatever, regional language, but something that translates without using complex language to people is something that we need.
There's more interdisciplinary research and sharing of information that is needed.

Of course, as I said, we have a lot of discussions on this matter, but the question is key, how applicable is this research, how generalizable these researchers are in order to provide the social support, how well it is translating, you know, into the social support provision that is needed,
in the ground.
So, my suggestions, of course, would be increase research and social processes of treatment, not just the medical processes, designing a social care system and fostering uniformity and value of life.
The third one, it comes from a place where I have, from what I understand, from what I hear, is often comes from the point of view key when the person is an older patient, there's less value given to their lives, as compared to, you know, younger person,
to, you know, younger patients on college care.
So, trying to also move towards a place where we, you know, have a universal value to human life is something we would need in order for people to even start caring for providing social support to geriatric patients.
So, in terms of research, as I said, there needs to be evidence-based interventions designed for social care.
Assessments are needed. There are a lot of assessments out there, but I honestly am not very sure about, because one question when I asked when I met Bonita was, how will you assess validity of our questionnaire?
How will we know that it is actually giving us the kind of information we need?
Questioner, Bennega, we have translation and accuracy, consistency and responses, does not mean that it is actually measuring what we want to measure.
So, it is very important that, you know, if we use assessments, we do start thinking about its validity.
Then, in terms of care, what kind of care can we provide?
Indigent interventions, of course, a lot of us have spoken about.
CBTR-EBT, fine, but there is, it's given too much importance, to be very honest.
I remember a horrific wiver where my student is like,
Skidofintaklissi-Rupc-Bt-R-EBT-Keringue, and I was like, please, I am not passing with this kind of answer.
There are a lot of other kind of intervention systems available in terms of existential therapy.
There is dignity therapy, there is hope-based interventions.
A lot of interventions, positive psychology, which is going to be difficult to quantify, because not as concretely
as concretely as concretely as concretely as concretely as concretely as concretely as concretely.
So, this is the problem that people are facing in palliative care.
They are facing problems of hope, they are facing problems of dignity.
They are facing problems of, what is my life about right now?
Group interventions, support groups, could be very helpful.
So, for those who can't afford admitting people into palliative care full time or something like that,
maybe group-based interventions could be helpful, where it could be interventions for patients,
or group-based interventions for patients who come together and talk about their experiences or even for caregivers,
because caregivers also experience a lot of stress, and for them group-based interventions could be very helpful.
And this can also be a very good way of inculcating skills in the caregivers of geriatric cancer patients.
And finally, when we talk about value of human life, it is important to understand the complexity of your patients' lives,
not just from what are the variables that has been very prominently discussed in the medical field,
but variables which are not discussed in the medical field.
Economic class, caste, sexuality, gender, all these things matter a lot in terms of

patient care,
and this of course translates to even geriatric patient care.
And as I said, it's important that in our discussions of value, we talk about dignity, we talk about hope, we talk about inclusion.
And yeah, that is my talk.
And thank you so much for the amazing work that TMH is doing with the patients and giving this platform for discussion.
Yeah.
Yes, please.
All right, so I wanted to ask about your thoughts on, you know, you were saying how culturally it's different in India,
and we don't know about the validity of scales, right?
So I'm just wondering, can you speak more towards those cultural variations, like for example,
alienation, loneliness, and how these can be connected back to social support,
and how do you propose to help measure those aspects?
Okay.
So in terms of cultural variations, now for example, let's talk about, I mean, a lot of you are from Mumbai,
but for those who are not from Mumbai, let's, so there are, you know, your middle class suburban areas,
and you have like your distant with, what's the other side, you know, but the upper side where you have people who are,
who belong to lower socio-economic strata.
So now here, the ideas of, you know, alienation, for example, there's alienation already being experienced when you belong to
socio-economic strata, which has anyway been marginalized, and that leads to a different way of dealing with such kind of,
you know, situations where part of it already is support because marginalization kind of sometimes brings people together.
And there is better social support, in fact, you know, there's better coherence amongst individuals who belong to these communities,
as compared to, let's say, a suburban, you know, Mumbai house from a middle class family,
where which actually may experience more isolation.
We often think of individuals from marginalized communities, for example, as more, you know,
disenfranchised and with less, you know, what do you say,
means of seeking social support, but actually we may actually, some, has to learn from how community building works
over there and apply those principles may be over here, in our case of dealing with other sections of society too.
Okay, and I wanted to ask you about your thoughts on participatory action research.
I mean, is that an angle that you intend to take?
Could you clarify what you may participate in?
So, it's basically where you have the questionnaires are co-created by the patients and the caregivers themselves.
Absolutely.
So, that's, yes.
Yeah, because I don't think you should have just one expert, you know, sitting in the armchair and thinking about
the possibilities out there.
Even the social support scale that we are building, we are trying to first, we start with the, we're starting with the qualitative study first
to understand the experiences of the patients and from there we are generating items instead of thinking theoretically speaking
what are the possible items?
The thing is that, you know, when you're designing that and then you're also going to the next phase,

so this approach will allow for the participants themselves to also weigh in on the scale, right?
Yeah, yeah, yeah.
So, it's an active, you know, they become co-creators of that scale.
Yeah, so face validity for example is something that we are going to look into and also having some sort of forward and backward
translations from the patients in terms of whether they're understanding the items well, whether it's translating into what they are, you know,
whether or not it's something that we are taking a conversation.
And your expert group also can be patients who will be so excited.
Yeah, absolutely.
Yeah, but I think also, sorry, just one last thing is that the concept of social communication is something that, you know, is also very important
to kind of explore because as you were saying, economic variation does not play a role in terms of the lack of or the need for communication
within oneself.
And more than isolation, alienation is also an issue that, you know, stigma and all those kinds of things need to also be embedded into a social
support questionnaire within India especially.
So, something to also explore, right?
Yes, true.
I completely agree with that.
And also because I think often there is an entrenchment of superiority that, you know,
I have seen, so because I teach clinical psychology, so I've seen that psychology, psychiatry,
Kisajab, interaction, Sotha, there's always a sense of hierarchy that's there.
I think a more collaborative approach is a better way to go rather than a hierarchical approach and that's where it is important
that, you know, that's why I said that communication needs to be given even for medical professionals.
We can't show responsibility saying that our job is just medical professionals, so we will not, you know,
deal with the communication part.
Yeah.
Yeah, sure.
In the clinic scenario which many would put in it, so say we've got a late 15, 60 year old patient
accompanied by three sons, three daughters of an extended family, a clearly very good social support.
Maybe.
That's the question, yeah.
But it doesn't do well and you know, you can see during the rounds that there is a civil anxiety and negativity
and various things which are happening.
And in another scenario where we have an, you know, eight year old lady coming with just one, you know,
teenage grandson gets a super major surgery and goes out of the hospital without any events.
We often talk about resilience.
Is that an objective thing?
Is it something which can be measured?
That's one.
Because I think particularly for the Indian population, if there is an objective way of measuring resilience
or that can be devised, that will be very relevant for our population because many of our patients do,
where despite the odds, that's one.
The second thing is that we always tend to go together as a psychosocial, I mean,

on our talks and things and measurements
but I think for our population probably the psychoanalysts social part are different.
They are two different parallel and they could be divergent as well.
Okay.
So.
This came on either topic or it gave to driver social, he added the psychoanalysts.
Yeah.
Resilience, yes.
I mean, there are definitely a lot of constructs on resilience measurable ones.
India, not very sure, but also an interesting point I came across a few days earlier, having a workshop
on ground realities of mental health, about resilience.
Sometimes resilience ends up becoming a barrier to communicate lack of support because we can't really, you know,
when there is, families will not pay attention when you are holding on and you're not saying anything about lack of support
and that may qualify as a high resilience thing and that of course becomes easier to think of, again,
it's easier to put the responsibility on the individual and leave it at that because it is difficult to involve the family
because there's a whole complex, you know, dynamics of people that is much more difficult to deal with
but resilience, of course, could be helpful in terms of helping with maybe treatment adherence and things like that.
So that people don't really give up easily but it can be a doublet sword in terms of whether or not then are they holding back
from seeking support or the need.
Yeah.
Thank you.
Yes.
Thank you for a nice topic.
Actually, I would like to make a small company.
This is a good initiative for psychosocial assessment, you know.
But when we consider about the psychosocial assessment, so we need to, and this is definitely good,
but we need to consider that the feasibility, you know, but when patient comes, first that patient is elderly,
he has a lot of como-obigrities.
He, I mean, he advised me some chemotherapy, you know.
So in my setup, I can say that we do some psychosocial assay without scale and that support also.
I can give a small example and briefly that as you were telling somebody that old lady, that it doesn't have a, I mean, son, he has,
she has that son and the daughter but she always attends with a grandson and he is just 12 years old.
So he stopped his schooling. I mean, he has discontinued his schooling. He is from West Bengal.
Okay.
And so that we need to speak because that child, that he doesn't know, he is not that much aware of the importance about his continuing of education.
So we need to support and psycho-jicate that why is here and that somebody should be with her.
Yes.
You know, somebody should be with us so that he can continue schooling.
Second thing, that some patient that, I mean, that children, that they are not with the old patient, I have seen some patient that recently,
that they, that, I mean, elderly patient, he has two sons.
He says they are living in Mumbai, he has staying in Mumbai, but still patient is

staying on road.
So we, so we highlight those issues.
We help them. Somebody has financial support so that we, that navigate through our medical social worker and that we, I mean, we have continued to follow whether that issues has been resolved.
So what I intend to say that we do some sort of psycho-social, uh, assessment along with support.
Okay.
Thank you.
Thank you so much for it.
One last thing I'd just like to add, key, which kind of relates to my point of trying to, um, anchor this meeting or anchor this talks in some, you know, some sort of context is that, uh, very important points that when he had made right in the beginning of the first talk was
institutional incentive and patient advocacy.
Um, we cannot expect, you know, um, any sort of social support, better difference to be made if we just discuss it.
And if we just talk about, I mean, um, I think it was often a, so I teach and there's, of course, medical professionals.
I think both these professionals are considered noble and this nobility is associated with a lot of sacrifice constantly.
And there's a sort of guilt that's associated with asking for better infrastructure because there's always seen as something, oh, you're a noble person.
It should be, you know, dedicating your life, but there's certain, uh, structural realities which cannot, you know, work without, uh, any sort of aid, any sort of funding.
And it is important that as, as a fraternity, that we do, when we are in, uh, and I'm, I'm sure all of us are in important positions, uh, we do have to push.
We have to push for better, uh, you know, because we can reach places, uh, you know, wherever voices can be heard by, you know, um, in policy making.
And it is important that we do talk about it, um, you know, and give this, these things, uh, the spotlight that it needs.
So, yeah, that's all I have to speak about today. Thank you.
Yeah. Thank you, then.